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Disability Rights and Independent Living Movement Oral History Series

BUILDERS AND SUSTAINERS OF THE INDEPENDENT LIVING MOVEMENT IN BERKELEY
VOLUME IV

Janet Brown	STUDENT MEMBER OF THE NATIONAL FEDERATION OF THE BLIND AND FIRST NEWSLETTER EDITOR FOR THE CENTER FOR INDEPENDENT LIVING, 1972-1976
Phil Chavez	PEER COUNSELOR AT THE CENTER FOR INDEPENDENT LIVING, 1970s-1990s
Frederick C. Collignon	UC PROFESSOR OF CITY AND REGIONAL PLANNING: POLICY RESEARCH AND FUNDING ADVOCACY
Hal Kirshbaum	DIRECTOR OF PEER COUNSELING AT THE CENTER FOR INDEPENDENT LIVING
Michael Pachovas	BERKELEY POLITICAL ACTIVIST, FOUNDER OF THE DISABLED PRISONERS' PROGRAM
Raymond "Ray" Uzeta	INDEPENDENT LIVING CENTERS IN BERKELEY, SAN FRANCISCO, AND SAN DIEGO: PERSPECTIVE ON DISABILITY IN MINORITY COMMUNITIES

Interviews Conducted by
Sharon Bonney
Graham Johnson
Mary Lou Breslin
and Kathryn Cowan
1997-1999

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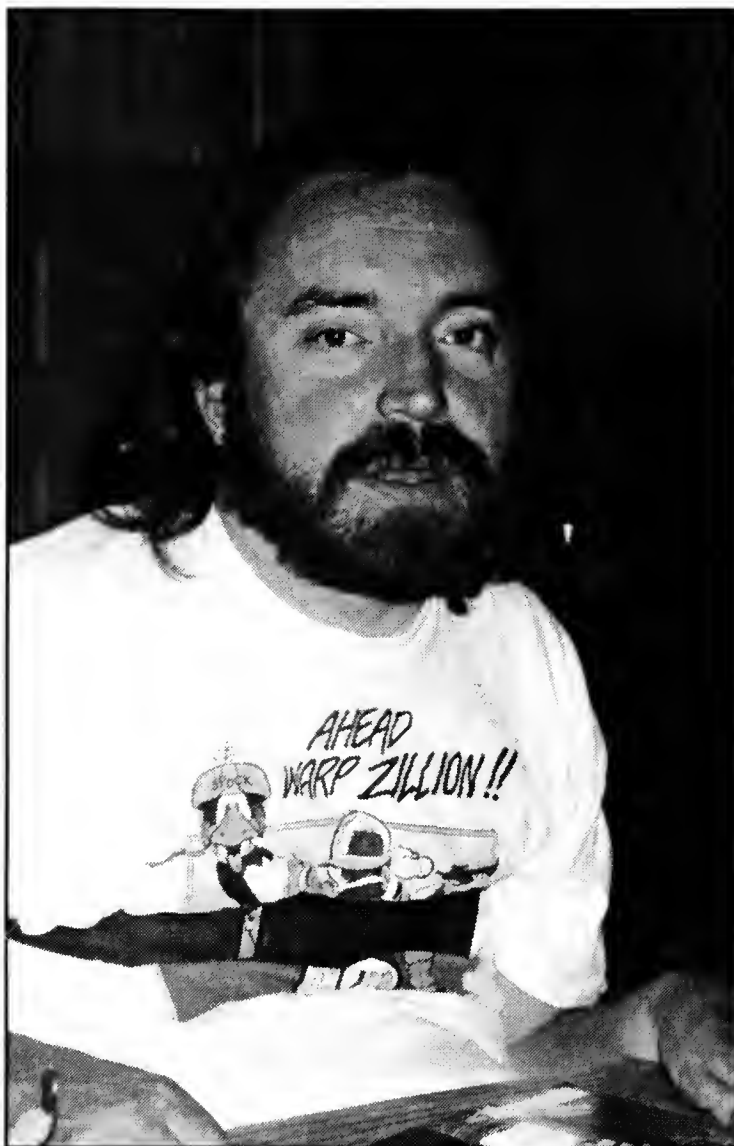
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TABLE OF CONTENTS--Builders and Sustainers of the Independent Living
Movement in Berkeley, Volume IV

SERIES INTRODUCTION by Simi Linton	i
SERIES HISTORY by Ann Lage and Susan O'Hara	vii
SERIES LIST	xiv
INTERVIEW WITH JANET BROWN <i>Student Member of the National Federation of the Blind and First Newsletter Editor for the Center for Independent Living, 1972-1976</i>	xix
Table of Contents	xx
INTERVIEW WITH PHIL CHAVEZ <i>Peer Counselor at the Center for Independent Living, 1970s-1990s</i>	29
Table of Contents	30
INTERVIEW WITH FREDERICK C. COLLIGNON <i>UC Professor of City and Regional Planning: Policy Research and Funding Advocacy</i>	68
Table of Contents	69
INTERVIEW WITH HAL KIRSHBAUM <i>Director of Peer Counseling at the Center for Independent Living</i>	159
Table of Contents	160
INTERVIEW WITH MICHAEL PACHOVAS <i>Berkeley Political Activist, Founder of the Disabled Prisoners' Program</i>	192
Table of Contents	193
INTERVIEW WITH RAYMOND UZETA <i>Independent Living Centers in Berkeley, San Francisco, and San Diego: Perspective on Disability in Minority Communities</i>	324
Table of Contents	325
TAPE GUIDE	356
INDEX	358

SERIES INTRODUCTION--The Disability Rights and Independent Living Movement, by Simi Linton

When I was asked to write the introduction to the Bancroft Library's oral histories on the disability rights movement in Berkeley, it reminded me of the summer of 1975, when I left New York City and headed out to Berkeley, California. For Berkeley was the place to be I told my friends, filled with hippies and free love. I would spend the summer, take courses at the university. I had been disabled just a few years and this was my first trip on my own, away from the tight circle of family and friends I had relied on in those early years.

Someone had told me that Berkeley was a center of disability activism, but I didn't tally that in my list of reasons to go there. I was a naive young woman in my twenties, and still new to disability. I "managed" my disability by keeping its profile low, and its needs in check. I use a wheelchair, and did then, and decided I would need to call the disabled students' office at the university to get help finding an accessible apartment near the campus, but also decided this would be the only concession I would make to my disabled state. I was fine, I told myself and my family, and by that I meant I could go anywhere, I could do everything. Disability would not bog me down and it would not mark me.

While bold on the outside, I harbored the deep fear that I might fail in my ability to keep disability in its place, that it would come crashing in around me and swallow me up. I, therefore, was completely unprepared for the headlong leap I made that summer toward disability, toward the people and the territory that I had shunned. I never imagined that I would move toward disability with interest and gusto. It didn't happen all at once in that brief summer, but I call that time in Berkeley my coming out.

I had arrived in a place where disability seemed more ordinary than it was where I had come from, where accommodations were apparent, where the curbcuts on every corner made it possible for me to go to the supermarket, to the bookstore and up to campus without having to stop someone at each corner, explain to them how to tilt my wheelchair back, take it down the curb, and lift it back up on the other side. Although Berkeley may not have had significantly more disabled people than other places, it seemed to. Maybe it was because I was out on the streets more than I was in New York. I saw people acting out the daily routines of life--going to the supermarket, school or their jobs--using wheelchairs or crutches, brandishing white canes, using sign language and all of the other indicators of membership.

And life started to become easier and more flavorful, not by avoiding disability but by living with it in a different way. The lure of the other disabled people I saw was great, and I learned that it was those people, most I never got to meet, who were responsible for the curb cuts, accessible bathrooms, the independent living center where I went for help, and the disabled students office that had found an apartment for me. I had never seen any place where disabled people were in charge and it thrilled me and made me optimistic about my life in a way that no other experience could.

I learned back then that it was not some benevolent church group that carved out those curb cuts, or a member of the town council trying to get votes who mandated accessible facilities, they were due to the deliberate actions and painstaking labor of members of the disability community who fought for the changes that were made. Their work set the stage for the ongoing struggle for rights and liberties that has engaged a nation of activists. Today, while discrimination remains a constant in disabled people's lives, the right to an accessible environment, to housing, employment, and transportation is governed by laws that are increasingly exerting influence on those who discriminate. Further, the idea of integration, in education, in public accommodations and in transportation, pervades the informed discourse on disability rights and is supported, again, by legislation that mandates desegregating society.

The Bancroft Library's Regional Oral History Office project, "The Disability Rights and Independent Living Movement: The Formative Years in Berkeley, California, 1960s-1980s," exposes the brick and mortar of these victories. Present in the narratives are major players and significant events, as well as the vital auxiliary figures and contributing influences that form the connective tissue of the Berkeley portion of these movements. The histories also reveal the dilemmas and roadblocks that halted progress and interfered with the integrated and equitable society that the framers of this political agenda envisioned.

It is a critical time to look closely at the progress that has occurred, and to study the impairments and deficits that remain in our not yet fully integrated and equitable society. Researchers, activists and those who write policy need, of course, to examine the present moment, and evaluate the necessary steps to take to move forward. Yet, just as important, is an examination of what led us here. How are present problems connected to past struggles? How do ideas that we act on today, relate to those formulated in past eras?

The oral history project provides detailed answers to those research questions. The material they have assembled will be of value to researchers, artists of all kinds, activists and policy makers. This endeavor is made possible now by opportunities afforded by the present moment that were not readily available before. The early activities and ideas have had the opportunity to grow and take root. There has been

time to evaluate their impact and to see the shifts in ideas, policy, and human interactions spurred by what at first glance might seem to be a random set of activities undertaken in reaction to specific concrete problems.

In addition, there have been a number of developments over the last three decades that have created both the need and the impetus for this work. I've grouped these into four sections that outline some of the cultural, scholarly and political activity that informs this work.

The Social Construction of Disability and the Significance of Community

What I witnessed in the summer of 1975 when I came to Berkeley from New York was that disability could mean something different just by moving to a new location. I wouldn't learn the term "social construction" for another fifteen years, but I did learn through direct experience that disability is not fixed. I also learned that the disability community is a powerful and meaningful entity.

Fundamental to the Regional Oral History Office project is an understanding of the social construction of disability. The efforts begun in the sixties by the people interviewed here to reframe disability as a social designation and to conceptualize obstacles to employment, education and integrated living as a civil rights issue, rather than an individual problem of impairments and deficits, made it possible to understand disability that way. Further, an essential prerequisite for the progress of the disability rights movement was the organization of the disability community, a coalition formed by the discovery of each other and the recognition of our common social status. Although medical and educational institutions continue to categorize and divide people by impairment status, the formation and the formulation of the "disability community" has had a major impact in the social/political arena.

For all my early learning, and my ongoing study of disability, it is in reading these histories that I have begun to understand how profound and original the ideas are that drove the early activists. The voices that are heard here demonstrate the purposefulness of the activists and their comprehensive vision of an equitable society. If this research platform were to reveal nothing else, it would be invaluable as a means to contradict the stereotypes of disabled people, and of the disability rights movement as merely riding the coattails and mimicking the agendas of the civil rights and feminist movements.

Yet, not only does this collection of histories serve as an exemplar of social construction and the significance of community, it demonstrates the unique nature of the construction of disability and illustrates the struggle to define and assert rights as a minority group

in the face of powerful efforts to confine disability within the province of medical discourse.

The Value of First-Person Narratives

A second domain that informs this project is the increased attention to the active voice of previously marginalized peoples. First person narratives, long discredited in academic circles, are now accepted by a wide variety of scholars and public historians as not only valid, but necessary research tools. ROHO's intent to bring disabled people's perspective to the forefront is consistent with that approach, and the nuanced and detailed data they obtained demonstrates again the value of the methodology. Disability has traditionally been studied as the effect of war or violence, the failures of medicine, or other causes. In these narratives, we see that what brought disability to the individual becomes much less important than what the presence of disability causes to happen. Significantly, the narrators show the ways that disability sets in motion certain social and institutional responses. As these histories reveal, a disabled person's presence in a school, a restaurant, a job interview, a social gathering, or other venue often caused events to unfold in particular ways.

While scholars outside of disability studies have rarely paid attention to disability narratives, this project provides compelling documentation of the place of disability within the larger social arena, and also demonstrates the ways that disability plays a role in shaping an historic moment. I believe that the rich insights of the narrators and their ability to reveal the complex consequences of disability oppression will engage scholars within disability studies as well as those outside the field. For instance, researchers might want to look at what the histories reveal about the parallels between the place of women in other early civil rights struggles and in the disability rights movement. They may want to examine disabled people's perspective on their exclusion from other social justice platforms or consider the obstacles that the disability community itself may have erected to coalition building with other disenfranchised groups.

Complex Representations of Disability and the Social Milieu

The oral histories provide detailed descriptions of the lives of the narrators and others in their circles. These materials will be useful not only to researchers and activists but to writers and artists interested in portraying the lives of the people interviewed, or developing fictional representations using these figures as stimuli. For instance, writers can turn to these histories for background information for projects that dramatize events of the sixties. The projects might relate specifically to the events or the people described in the oral histories, or the research might be aimed at gaining more accurate information about secondary characters or events. A writer

might want to learn more about what the Cowell Residence really looked like, who lived there, what were the attendants like, some of whom were conscientious objectors doing alternative service during the Vietnam War, or what kinds of wheelchairs and other adaptive equipment were people using then. These histories are about disabled people and the genesis of the disability rights movement, but they are also histories of the period and will be useful in providing more accurate representations of both.

While mainstream cultural products continue to depict disabled people and disabled characters in inaccurate and narrow ways, a growing number of writers, artists, actors, and performance artists who are disabled or are insiders in the disability community are providing more realistic, interesting and complex representations of disability to a wider audience than the arts ever have before. Although the numbers are still small and the venues marginal, I expect that over the next decade, as increasing numbers of disabled people gain access to higher education and training in the arts, their ranks will grow and as they do, this material will continue to grow in value.

A Resource for Disability Studies Scholars

Finally, this project will be an invaluable resource to the growing ranks of disability studies scholars. Disability studies began to take shape as an organized area of inquiry in the early 1980s. Prior to that time, although there were isolated pockets of transformative scholarship in some liberal arts fields, the study of disability was housed almost exclusively in the specialized applied fields (rehabilitation, special education, health, et cetera). Disability studies came along and provided a place to organize and circumscribe a knowledge base that explains the social and political nature of the ascribed category, disability. The field has grown enormously, particularly since the early 1990s, as has the Society for Disability Studies, the organization that supports the work of scholars and activists interested in the development of new approaches that can be used to understand disability as a social, political and cultural phenomenon.

Certain ideas pervade disability studies. For instance, a number of authors have examined such ideas as autonomy and independence. The perspectives employed in a disability studies analysis of such phenomena afford a complex look at these hitherto rarely examined ideas. Scholars interested in the theoretical implications of these ideas will benefit from examining the ROHO histories. They will learn, as I did in a recent reading, how the early activists discovered that the surest route to gaining independence was to have access to attendant care. These young people, many just out of institutions, or living away from home for the first time in their lives, were creating a new type of community, one in which it was clearly understood that support and

services are necessary for individual autonomous functioning. They recognized the irony that what is typically thought of as "total dependence" was instead the ticket to the greatest freedom and autonomy they'd ever known. Rather than wait for the nurse or orderly in their institution to "decide" if it was time to get out of bed, have a shower, eat dinner or watch television, with personal attendants available and under their direction they could make these decisions on their own. Rather than wait at home for their mother or other relative or friend to bring them food or take them somewhere, they could lobby the university for a lift-equipped van that would be at their disposal and provide them with access to the kinds of leisure activities non-disabled students take for granted. They learned by setting up their own wheelchair repair services, and hiring qualified mechanics, they could keep their manual chairs, and the power wheelchairs that they also had lobbied for, in working order.

Through their lived experience they had the occasion to formulate a new way of thinking about such accepted ideas as what constitutes independence; what is freedom, equity, and integration; the ways that physical dependence and psychological independence are two separate and potentially unrelated variables. Disability studies, while dominated by theoretical formulations, social science research methodology, and modes of analysis employed in various areas of the humanities, will benefit enormously from the concrete examples given here of the abstract principles our work depends on.

The value of this project will ultimately be revealed as future research, creative endeavors, and policy initiatives are developed that have utilized this primary source material. Over the decades to come, researchers in all areas of inquiry will find within these documents numerous variables to be tested, relationships among people, events, and trends to be examined, cultural phenomena to be studied and dramatized, and ideas to be woven into theory or literature. The most exciting research opportunity that this work affords is the examination of the beliefs and behaviors of people whose demands for equity and justice upped the ante in the fight for an inclusive society.

The Regional Oral History Office staff are to be commended for their vision. They have brought us a vital piece of history, one that would be lost and forgotten if it were not for them. They have captured in these individual histories, a history. And a legacy.

Simi Linton, Ph.D., Co-Director
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New York, New York
April 1999

SERIES HISTORY--The Disability Rights and Independent Living Movement
Oral History Project, by Ann Lage and Susan O'Hara

Historical Framework

The movement by persons with disabilities for legally defined civil rights and control over their own lives took on its present framework in the 1960s and 1970s. Virtually simultaneously in several cities nationwide, small groups of people with significant disabilities joined together to change the rules of living with a disability. No longer content with limited life opportunities, nor willing to be defined solely as medical patients, they shared the willingness to challenge authority, discard received wisdom, and effect societal change that was the hallmark of the era. Not surprisingly, the disability movement paralleled other movements for equity and civil rights by and for racial minorities, women, and gay people. From our vantage at the close of the century, it is apparent that these movements, taken together, have changed the social, cultural, and legal landscape of the nation.

Berkeley, California, was one of the key cities where models for independent living were developed. A small group of young people, all wheelchair users, had one by one enrolled at the University of California in the 1960s. In an era prior to accessible dormitories or private housing, they were given living quarters in the campus's Cowell Hospital. In the midst of the campus maelstrom of free speech, civil rights, and anti-war protests, they experimented with radical changes in their daily lives, articulated a new philosophy of independence, and raised their experience to a political cause on campus and in the community.

By 1972, these students had created new institutions, run by and for people with disabilities, which soon attracted national attention. The first two of these organizations, the Physically Disabled Students' Program on the campus and the Center for Independent Living in the community, drew several hundred people with disabilities to Berkeley from across the United States. This early migration became the nucleus and the strength of the community that, for many, came to symbolize the independent living movement.

Political action kept pace with the developing awareness and institutional growth. In the early seventies, the Berkeley group successfully lobbied the city of Berkeley for curb cuts and the state legislature for attendant care funding. In 1977, scores of persons with disabilities sat in for twenty-six days at the offices of the federal Department of Health, Education, and Welfare in San Francisco, as part of a nationwide protest that eventually forced implementation of Section

504 of the Rehabilitation Act of 1973, often called the Bill of Rights for Americans with Disabilities. Many participants trace their awareness of disability as a civil rights issue and their sense of membership in a disability community to the 1977 sit-in.

By the 1980s, a number of other important organizations had evolved from the Berkeley experience: the Disability Rights Education and Defense Fund (DREDF), the World Institute on Disability (WID), Computer Training Program (later, the Computer Technologies Program [CTP]), the Bay Area Outreach Recreation Program (BORP), and others. All of these organizations shared the original philosophy of the Berkeley movement. Their example and their leaders have had national and even international impact on the quality of life and civil rights of persons with disabilities.

Genesis of the Project

The idea for a project to document these historic events germinated for nearly fifteen years before funding was secured to make possible the current effort. In 1982, Susan O'Hara, then director of the Disabled Students' Residence Program at the University of California, Berkeley, contacted Willa Baum, director of the Regional Oral History Office (ROHO) of The Bancroft Library, suggesting that the genesis of the Berkeley movement be recorded in oral histories with participants in the campus's Cowell Hospital Residence Program. Mrs. Baum and Ms. O'Hara began planning, enlarged the project scope, gathered faculty support, and initiated the search for funding. Their efforts produced three grant applications, the final one in cooperation with Professor Raymond Lifchez of the UC College of Environmental Design, to the National Endowment for the Humanities, none successful.

ROHO then secured funding from the Prytanean Society, a Berkeley campus women's service group, to produce oral histories with Arleigh Williams and Betty Neely, both campus administrators who oversaw the establishment of the early disabled students' programs. Herb Wiseman, a former staff member of the disabled students' program, conducted these two interviews in 1984-1985. Later, the California State Archives State Government Oral History Project funded an oral history with Edward Roberts, the first student in the Cowell program and later the director of the California State Department of Rehabilitation. This initial support proved essential; all three individuals were to die before the current project was funded.

By 1995, as the historical importance of the events in Berkeley and beyond grew increasingly evident, the fragility of the historical record became ever more apparent. The archival records of key institutions that grew out of the movement and shaped nationwide events were not collected and preserved in a publicly accessible library. The

personal papers of key leaders of the movement were scattered in basements and attics. Moreover, the urgency of preserving the memories of participants through oral history interviews was underscored by the death of five pioneer disabled activists in the previous several years.

When Susan O'Hara and Mary Lou Breslin outlined the scope of the problem to The Bancroft Library, the then-curator of Bancroft Collections, Bonnie Hardwick, joined Willa Baum in support of the idea of developing a comprehensive disability collection at Bancroft. Baum, Hardwick, and Ann Lage, associate director of ROHO, worked with leaders of the disability community to design a plan for an archival collection at The Bancroft Library, to include both in-depth oral history interviews and written and photographic records of major organizations and activists. The Disabled Persons' Independence Movement collection was envisioned as "a primary historical resource of national significance, a research platform for future scholars, for persons with disabilities, and for public education." The National Institute on Disability and Rehabilitation Research generously funded the three-year project in 1996.

Project Staff and Advisors

The collaborative nature of the project--among the disability community, academic advisors, oral historians, and archivists--has strengthened it in every respect. The advisory board included three Berkeley professors: Frederick Collignon of the Department of City and Regional Planning, who has worked on disability issues since 1970; Raymond Lifchez, Department of Architecture, who has conducted research on environmental design for independent living since 1972; and William K. Muir, Department of Political Science, who has chaired campus committees on disability issues, and is a scholar of U.S. and state government and public policy. Paul Longmore, professor of history from San Francisco State University and a specialist in disability history, was crucial in defining themes and topics to explore in oral history interviews. Mary Lou Breslin, president and co-founder of the Disability Rights Education and Defense Fund, represented the perspective of the organizations to be documented as well as her personal experiences as an activist for disability rights.

Knowing that oral history is most often successfully carried out by persons who combine a compelling personal interest in the project with an ability to bring a historical perspective to their task, the Regional Oral History Office turned to the Bay Area disability community itself to staff the project's team of interviewers. Susan O'Hara became the historical consultant for the project and conducted a number of interviews as well as informing all of the project activities. All of the project interviewers had personal experience with disability. A majority had significant disabilities, several had participated in or

observed the historical events to be documented and knew many of the key players and organizations. Interviewers included Sharon Bonney, former director of the Disabled Students' Program at UC Berkeley and former assistant director of the World Institute on Disability; Mary Lou Breslin, who crossed over from the advisory board; Kathy Cowan, librarian for a public-interest nonprofit organization; Denise Sherer Jacobson, a writer and educator on disability issues; David Landes, a college instructor of economics and coordinator of student affairs for the Computer Technologies Program.

Joining the team to interview narrators in Washington, D.C., was Jonathan Young, a Ph.D. candidate in American history at the University of North Carolina who had conducted oral histories on the history of the Americans with Disabilities Act. When Mr. Young resigned to accept a White House appointment, Susan Brown, long familiar with disability issues and other civil rights/social movements, became the project's Washington connection. Ann Lage coordinated the interviewing team for the Regional Oral History Office, and the office's regular staff, coordinated by production manager Shannon Page, provided transcription and other clerical support.

Bancroft Library project personnel included Bonnie Hardwick, curator; Lauren Lassleben, supervising archivist; and Jane Bassett, the project archivist whose job it was to contact the disability organizations, project interviewees, and other activists and survey their records to identify historical material. Once records and personal papers were donated to the Library--more than 300 linear feet before the project's conclusion--it was Jane and her student assistant, Amber Smock, who preserved, organized, and made the papers accessible to scholars with detailed finding aids. The archival and oral history projects, though separately administered, were in close cooperation, with the interviewing team providing contacts with the disability community and leads on papers to collect and the archivists assisting interviewers in their research in the growing collection of written records.

Interviewees and Themes

An overarching question for the project was to explore and document how this social movement developed in time, place, and context: how the movement in Berkeley was built, how it became effective, how individual life experiences contributed to and were changed by the movement. Lines of inquiry included identity issues and personal life experiences; social/economic/political backgrounds of individual activists; the roles of women and minorities in the movement; development of leadership; institution building and management; development of a disability community group identity; media, mythology, public image and the political process; impact of technology; the range

of efforts to influence disability law and policy and to embed disability rights into the canon of civil rights.

Interviewees (narrators) were selected for one of several reasons: the individual was a founder or recognized leader of one of the key institutions, made a unique contribution to the movement, was a particularly keen observer and articulate reporter, or was a sustainer of the movement who provided a unique perspective. We attempted to choose narrators who had a range of disabilities and to interview nondisabled persons who contributed significantly to events or institutions.

Interviewees fell primarily into two categories: either they were involved in the residence program of Cowell Hospital on the Berkeley campus in the sixties or they participated in the building of early organizations in the 1970s.

Group One--UC Berkeley's Cowell Hospital Residence Program

A wing on the third floor of Cowell Hospital was the site of the first housing for students with significant disabilities on the Berkeley campus. This cluster became a breeding ground for the Berkeley phase of the independent living movement. About a dozen students--mostly men, mostly white, mainly in their twenties, with more and more autonomy within their grasp--spent several years in this benign but nonetheless isolated hospital residence, in the middle of a campus exploding with student protest movements. Six of these students were interviewed, including Ed Roberts, who narrated several hours of 1960s memories before he died with the oral history still in process. The former students all refer to their sense of community, intense camaraderie, the thrill of independence, an atmosphere of an-idea-a-minute, and the politics of their involvement.

Also included in this first group were certain early university and State Department of Rehabilitation officials--the hospital director, the nurse/coordinator, counselors--who might be called traditional gatekeepers but nonetheless allowed the unorthodox residence program to happen and in some cases encouraged it.

The majority of the narrators in the first group stayed involved in disability-related activities for many more years. Their recorded histories include these later activities, overlapping with the events documented in the second group of narrators.

Group Two--Builders of the Movement

The second group of interviewees are primarily founders and leaders who participated in the expansive phase which began in 1970 with the start of the Physically Disabled Students' Program (PDSP) at the university, followed by the founding of the Center for Independent Living (CIL) in 1972. These interviews reveal the grassroots politics, high energy, occasional chaos, unstinting belief in "the cause", seat-of-the-pants management, funding sources and crises, successes and failures of individuals and organizations. In the next few years a whole constellation of organizations evolved to sustain the independent living movement, including DREDF, CTP, KIDS, BORP, WID, Center for Accessible Technology (CAT), and Through the Looking Glass. This group of interviewees provide insight into the politics, leadership, and organization-building of both their own organizations and CIL.

Many key interviewees in this group are still in leadership positions and have had national and international impact on disability policy development. Also included in this second group are persons who were not in the top ranks of leadership but who were keen observers of the scene, could augment the basic history, and offer further points of view.

Oral History Process

All of the project interviewers received formal and informal training in archival oral history procedures and met monthly as a group to plan and evaluate interviews and review progress. Interviewers prepared a preliminary outline before each interview session, based on background research in relevant papers, consultation with the interviewee's colleagues, and mutual planning with the interviewee. In-depth tape-recorded interview sessions were from one to two hours in length; interviewees required from one to fifteen sessions to complete their oral histories, depending on the length and complexity of their involvement in the movement.

Tapes were transcribed verbatim and lightly edited for accuracy of transcription and clarity. During their review of the transcripts, interviewees were asked to clarify unclear passages and give additional information when needed. The final stage added subject headings, a table of contents, and an index. Shorter transcripts were bound with related interviews into volumes; longer transcripts constitute individual memoirs.

More than forty oral histories are included in this first phase of the Disabled Persons' Independent Movement project. Volumes can be read in the Bancroft Library and at the University of California, Los Angeles, Department of Special Collections. They are made available to

other libraries and to individuals for cost of printing and binding. Many of the oral histories are accompanied by a videotaped interview session to document visual elements of the interview and the setting in which the interviewee lives or works. Video and audiotapes are available at The Bancroft Library. If funding for a second phase of the project is secured, many of the oral history transcripts as well as a representative collection of documents and photographs will be available on the Internet as part of the Online Archive of California.

The Regional Oral History Office was established in 1954 to augment through tape-recorded memoirs the Library's materials on the history of California and the West. The office is under the direction of Willa K. Baum, Division Head, and the administrative direction of Charles B. Faulhaber, James D. Hart Director of The Bancroft Library, University of California, Berkeley. The catalogues of the Regional Oral History Office and many oral histories on line can be accessed at <http://library.berkeley.edu/BANC/ROHO/>.

Special thanks are due to donors to this effort over the years: the Prytanean Society; Raymond Lifchez and Judith Stronach; and June A. Cheit, whose generous donation in memory of her sister, Rev. Barbara Andrews, allowed the Regional Oral History Office to develop the grant project. The Bancroft Library's three-year Disabled Persons' Independence Movement Project, of which these oral histories are a part, was funded by a field-initiated research grant from the National Institute on Disability and Rehabilitation Research (NIDRR), U.S. Department of Education.

Ann Lage, Project Coordinator
Susan O'Hara, Historical Consultant

Regional Oral History Office
The Bancroft Library
University of California, Berkeley
September 1999

August 2000

Disability Rights and Independent Living Movement Oral History Series
The Formative Years in Berkeley, California

Single-interview volumes

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Joel Bryan, *Founder and Director of Disabled Students' Services, UC Riverside and UC Davis*, 2000.

Kitty Cone, *Political Organizer for Disability Rights, 1970s-1990s, and Strategist for Section 504 Demonstrations, 1977, 2000.*

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Judy Heumann, Deputy director of the Center for Independent Living, cofounder of the World Institute on Disability, assistant secretary of the U.S. Department of Education. (in process)

Arlene Mayerson, Directing attorney, Disability Rights Education and Defense Fund. (in process)

Pat Wright, Director, Governmental Affairs Office of the Disability Rights Education and Defense Fund, strategist for the Americans with Disabilities Act. (in process)

Multi-interview volumes:

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Herbert R. Willsmore, *Student Resident at Cowell, 1969-1970, Business Enterprises Manager at the Center For Independent Living, 1975-1977.*

Billy Charles Barner, *First African American Student in the Cowell Program, 1969-1973, Administrator in Disability Programs in Los Angeles.*

John "Jack" Rowan, *Student Resident at Cowell, 1971-1973, and Chair of CIL's Board of Directors, 1976-1982.*

Peter Trier, *Student at Berkeley: Transition from the Cowell Hospital Program to the Residence Halls, 1975.*

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Karen Topp Goodwyn, *Department of Rehabilitation Counselor in Berkeley, 1972-1983.*

Gerald Belchick, *Department of Rehabilitation Counselor, Liaison to the Cowell Program, 1970s.*

John Velton, *Department of Rehabilitation Administrator: Providing Oversight for the Residence Program, Fostering Career Placement and Computer Training, 1970s-1980s.*

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Linda Perotti, An Employee Perspective on the Early Days of the Cowell Residence Program, Physically Disabled Students' Program, and the Center for Independent Living.

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Hal Kirshbaum, Director of Peer Counseling at the Center for Independent Living.

Michael Pachovas, Berkeley Political Activist, Founder of the Disabled Prisoners' Program.

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Doreen Pam Steneberg, *Parent Advocate for Educational Rights for Children with Disabilities.*

MAINSTREAM MAGAZINE: CHRONICLING NATIONAL DISABILITY POLITICS, 2000.

Cynthia Jones, *Mainstream Magazine Editor and Publisher.*

William Stothers, *Journalist and Managing Editor of Mainstream Magazine.*

UNIVERSITY ADMINISTRATORS RECALL ORIGIN OF THE PHYSICALLY DISABLED
STUDENTS' RESIDENCE PROGRAM, 1987.

Arleigh Williams, *Recollections of the Dean of Students.*

Betty H. Neely, *Recollections of the Director of Student Activities and Programs.*

In Process, multi-interview volumes:

Neil Jacobson, *Cofounder of the Computer Training Project and Cochair of the President's Committee on Employment of People with Disabilities.*

Scott Luebking, *Cofounder of the Computer Training Project, Specialist in Accessible Technology. (in process)*

Maureen Fitzgerald, *Early Deaf Services Programs at the Center for Independent Living. (in process)*

Anita Baldwin, *Deputy Director of the Center for Independent Living, Early 1980s: Observations of Blind Services and Staff Strike. (in process)*

Joanne Jauregui, *Activist in the Deaf Community: Deaf Services at Center for Independent Living. (in process)*

VIDEOTAPED INTERVIEWS:

Mary Lou Breslin, Kitty Cone, Neil Jacobson, Joanne Jauregui, Deborah Kaplan, Johnnie Lacy, Joan Leon, Susan O'Hara, Zona Roberts, Ken Stein, Herb Willsmore, Hale Zukas.

Regional Oral History Office
The Bancroft Library

University of California
Berkeley, California

Disability Rights and Independent Living Movement Oral History Series

BUILDERS AND SUSTAINERS OF THE INDEPENDENT LIVING MOVEMENT IN BERKELEY
VOLUME IV

Janet Brown

STUDENT MEMBER OF THE NATIONAL FEDERATION OF THE BLIND
AND FIRST NEWSLETTER EDITOR FOR THE CENTER FOR INDEPENDENT LIVING, 1972-1976

An Interview Conducted by
Sharon Bonney
in 1998

TABLE OF CONTENTS--Janet Brown

INTERVIEW HISTORY	xxi
BIOGRAPHICAL INFORMATION	xxii
Birth in Berkeley, 1949; and Mainstreamed Elementary and Secondary School Years	1
Entry into UC Berkeley and the Tussman Program; Masters Degree from Holy Names College, 1973	3
Affiliation with the National Federation of the Blind and Coalition Building	5
Life as an Employee at the Center for Independent Living, 1972-1976	8
Job with Fair Employment and Housing	17
Employment and Fund-raising Practices and the Center for Independent Living's Legacy	19
Professional Life, 1981 to the Present	21
Reflections on the Independent Living Movement	24
More Thoughts on the Center for Independent Living	26

INTERVIEW HISTORY--Janet Brown

Janet McEwen Brown was a student at the University of California at Berkeley in the late 1960s, was the head of a student chapter of the National Federation of the Blind, and participated in developing the concept for the Center for Independent Living which was emerging in the minds of a small group of people in Berkeley. Janet is a founding member of the Center for Independent Living and she was one of its earliest employees.

Ms. Brown recalls discussions with people sitting around the table about what the center should be, who it should serve, and who should be a part of it, and she gives the reader a sense of motivation of the founding members and of their perceived need for the center. She describes the principles behind publishing the Independent, the center's newsletter and the desire for it to be on the cutting edge of the disability movement. She offers insights into the internal workings of the center, discusses attempts at building coalitions, and describes employment and fundraising practices. Perhaps Ms. Brown's history is most important for its glimpse into the thoughts of one founding member who was young and inexperienced, but who realized that disability issues were civil rights issues. She, and others, were "fighting for inclusion in the mainstream of society" without realizing at the time how extraordinary their actions were or how influential they would be.

The interview took place on March 13, 1998, in Ms. Brown's home in San Anselmo, California. The interviewer's tape recorder malfunctioned and Ms. Brown's recorder was pressed into service. There are several places on the tape where the dogs barked at passersby and at the mailman. The mantel clock, which was next to Ms. Brown's head, chimed every fifteen minutes. During the interview, Mr. Brown came home and fixed himself lunch and sounds of the preparation and the microwave beeping can be heard in the background. The Brown home is a sunny, bright, activity-filled home.

The interviewer edited the transcript and made very few changes or corrections. Ms. Brown asked that the interviewer read the transcript to her so that she could review and edit it as necessary. Transcript review and editing took place at the Center for Independent Living on September 10, 1998, for one hour. Janet made a few clarifications and corrections.

The Regional Oral History Office was established in 1954 to augment through tape-recorded memoirs the Library's materials on the history of California and the West. Copies of all interviews are available for research use in The Bancroft Library and in the UCLA Department of Special Collections. The office is under the direction of Willa K. Baum, Division Head, and the administrative direction of Charles B. Faulhaber, James D. Hart Director of The Bancroft Library, University of California, Berkeley.

September 10, 1998
Regional Oral History Office
The Bancroft Library
University of California, Berkeley

Sharon Bonney, Interviewer-Editor

Regional Oral History Office
Room 486 The Bancroft Library

University of California
Berkeley, California 94720

BIOGRAPHICAL INFORMATION

(Please write clearly. Use black ink.)

Your full name JANET BROWN

Date of birth 10-30-49 Birthplace Berkeley, CA

Father's full name William Joseph Milton Kirk McEwen

Occupation ASST. PROFESSOR at UC MED. SCHOOL Birthplace Winnetka, Ill

Mother's full name GERTRUDE JEAN ERNESTINE JOHNSON McEWEN KOENIG

Occupation Reading Specialist Birthplace MAYWOOD, ILL.

Your spouse CHARLES M. BROWN

Occupation N/A Birthplace PASADENA, CA

Your children N/A

Where did you grow up? Berkeley, CA

Present community SAN ANGELES, CA

Education BA, CAL, 1970; MA TEACHING CREDENTIAL, HOLY NAMES

MA IN PROGRESS in Counseling Psychology HOLY NAMES, 1999

Occupation(s) COUNSELOR

Areas of expertise _____

Other interests or activities CONTRA DANCE MUSIC, MANDOLIN
PLAYER,

Organizations in which you are active CAL. ASSOCIATION OF FAMILY

INTERVIEW WITH JANET BROWN

Birth in Berkeley, 1949, and Mainstreamed Elementary and Secondary School Years

[Date of Interview: March 13, 1998] ##¹

Bonney: This is Sharon Bonney, and I'm in the home of Janet McEwen Brown. It's Friday, March 13, 1998.

Jan, let's start out with you giving me a brief introduction to yourself. Where were you born and when? What was your childhood like?

Brown: I was born in Berkeley in 1949 and I was one of those premature kids who was given too much oxygen. I remember asking my parents as a teenager, "Did you ever come visit me? Or was I just a late miscarriage?" Teenagers know how to ask these terrible questions. They said no, that they were told not to come visit me because they thought at the time that I was going to die. I said, "Well, was I a late miscarriage? Huh?" They said no. Even if I was they weren't going to tell me I was.

Anyhow, I was the second of four kids and the only one with a disability. My parents got real involved with the Berkeley schools because at the time Jacobus ten Broek, who was the head of the NFB [National Federation of the Blind] locally and who taught at Cal [University of California at Berkeley]--I think he was head of it nationally; I don't remember--I went to high school with his kid, and she was horrid and I was pleased. Anyway, they told my folks and the parents of other blind kids that we should go to the blind school because that's where we'd get the best education. So my parents went to look at the blind school and saw these kids rocking back and forth and poking at their eyes. They said no. They worked hard and they got Berkeley schools to hire a resource teacher--actually she was an English teacher. She was an English

¹## This symbol indicates that a tape or tape segment has begun or ended. A guide to the tapes follows the transcript.

major who had her teaching credential. They said, "Learn Braille over the summer because you're going to teach all these first-graders." She said, "Fine. Great." And she was a wonderful teacher. We went there for reading and arithmetic and things. Other than that we were in the regular classrooms.

Bonney: So back in the fifties then?

Brown: Pre-mainstreaming.

Bonney: Yes. You were all in regular classrooms.

Brown: Yes.

Bonney: Why do you think Berkeley was so far ahead in that area?

Brown: Because our parents beat on them.

Bonney: Did ten Broek have any influence there?

Brown: No, he was the opposition. He wanted us all to go to the blind school, and my parents said, "Forget it, buddy." They wouldn't have talked like that, but that was what they said. At the time I didn't think much about it. We were the integrated Braille program--that's nice. And then we'd go play. And it was very important in my household that kids go play. Go play with your friends. Don't just hang around and whine that there's nothing to do; go make something to do. They tried to treat me as normally as anybody else.

Bonney: What were your parents' expectations for you?

Brown: To get a job. A professional sort of job. Go to college. Same as anybody else in our household, in our family. My dad taught at the medical center in the city. At the time Mom was a stay-at-home mom, but during my teenage years she went back to grad school.

Bonney: And studied what?

Brown: She tested reading for kids in elementary schools for years.

Bonney: What aspect of medicine was your father in?

Brown: Ophthalmology.

Bonney: Irony [laughs].

Brown: Well, it was on purpose. He started out in liquid fuels.

Bonney: And switched after you were born?

Brown: I think so, yes--as best I can tell.

Bonney: Now what about brothers and sisters?

Brown: I've got three sisters--one who is a year and a half older and one who's four years younger and another who's four and a half years younger than that.

Bonney: Do they still all live around the Berkeley area?

Brown: Nobody does. The oldest lives in Modesto, I live here, the one below me lives in Monterey, and the youngest--the baby--who is not a baby any more--turned forty; that doesn't make you a baby--lives in Eureka.

Bonney: So you were born and raised in your early childhood in Berkeley.

Brown: All of it.

Bonney: And you graduated from Berkeley High?

Brown: Yes.

UC Berkeley Class of 1970, and the Tussman Program; Masters Degree
from Holy Names College, 1973

Bonney: And then what did you do?

Brown: I went to Cal. I applied to some other places but I went to Cal.

Bonney: And got in?

Brown: Yes. I couldn't nowadays, but that's okay. I was in a liberal arts program: something they called the Tussman program, an experiment at Berkeley. It was a two-year--they selected eighty Letters and Science people and asked us if we wanted to become part of this smaller program. It sounded fine at the time. All you had to do was take your science over at the big U. We studied western civilization and philosophy and the Bible and the Federalist Papers and all this stuff. It was great.

Bonney: Now you were in a separate school than UC Berkeley?

Brown: No, at Cal. It was a program. A guy got a grant to run a program, and he selected eighty of us and there were six professors. Full professors, not T.A.'s [teaching assistants], who taught us for the first two years.

Bonney: After the two years--

Brown: I finished Cal.

Bonney: Okay. So you didn't get your degree from Cal then?

Brown: Yes, I did. From this program--it was a lower-division program. It expired--it probably wasn't even worth bringing up, but it was fun.

Bonney: That's interesting. I've never heard of it before.

Brown: That's because it doesn't exist anymore. There were two cycles of it, and we were the second cycle, and I guess that was as far as the grant took it. I guess; I don't know. Anyway, then I finished out Cal with a history major and didn't know what else to do. I figured I would be a teacher, I guessed, but I didn't want to go to the School of Education and then the Department of History, so I went to Holy Names [College] and got my teaching credential and master's in history.

Bonney: Holy Names is in Oakland?

Brown: Yes.

Bonney: What year was it when you graduated from there?

Brown: From there or from Cal?

Bonney: When did you graduate from Cal?

Brown: In December '70, and I started Holy Names in January '71. I turned in my thesis the day after McGovern went down to defeat. I graduated and went to the ceremony. I didn't attend Cal's, but I went to the other one in '73.

Affiliation with the National Federation of the Blind and
Coalition Building

Bonney: Now while you were at Cal, were you part of the Physically Disabled Students' Program [PDSP]?

Brown: We predated it. We were part of T-22, which was the blind students--they had a temporary building. I remember going to the house with this woman--she was old, you know, she was probably twenty-two, an English graduate student. I was going to get an apartment my second year at Cal. I wanted to know how blind people lived, because I had never been a grownup before. So I went to this woman's house--Judy Wilkinson--I don't know what happened to her. She was going to show me kind of how cool she was, you know, and everything went wrong. She was making me lunch and she messed up the coffee grinding, and I forget all that went wrong. She felt terrible. I thought, I'm so glad to see other people make these mistakes. It made me feel better, and it made her feel worse, but that's okay. I mean, not lastingly worse.

We called each other about things like tape recorders, about things like the National Federation of the Blind stuff. We were all involved in their legislative seminars. They were good seminars; they had had them frequently, and we were all up on whatever the legislation was that affected blind people. I didn't run into PDSP until around 1970 when I met David Konkell, who was part of what was later called the "Blind Component" at CIL. And Dick Santos was a strong NFB guy at the time, but he wasn't a student so he wasn't in our student chapter. We would go to conventions and things, and then Dave had told us about these other people, "crips," who were starting something that was going to try to be as good as us [laughter]. We said, "Let's go. Let's see what they've got going, and see whether we can have part of it because this is a coming movement. It sounds like they've got similar goals. Let's see if we can do a coalition." We tried, and we have been trying ever since.

Bonney: Tell me what the NFB was like in those early days.

Brown: It was pretty much like it is now. Real good at getting its agenda passed. Its agenda does not include anybody with any other disabilities. It makes no claims other than that. It doesn't pretend to but then not include people; it just doesn't include you. Blind people are blind people, and that's what's important to them. They're pretty militant about it. But they're good as far as they go. I don't like them and I'm not a member of them, but for what they are they are good.

Bonney: What were the coalition attempts? What were you trying to do?

Brown: Trying to bring the NFB student chapter--that was us. We would trade off heading, various ones of us--it's your turn this year, it's your turn that year. I took us out of the NFB officially. Kind of fun. At a convention I said that--I was righteous because I was young enough to be righteous--and I said something to the effect that these guys were not into coalitions and weren't considering anybody else's rights except blind people's, well then we're leaving. We did.

Bonney: So much for coalition building.

Brown: No, we left the NFB and went to build coalitions with--I mean, this is blind people leaving the NFB. So we were working on coalition with the Disabled Students' Program and this new community thing that we were inventing.

The Need for the Center for Independent Living

Bonney: Which was?

Brown: CIL [Center for Independent Living].

Bonney: Were you part of the group that wrote the proposal for the Disabled Students' Program?

Brown: No.

Bonney: But you were part of the group that wrote the CIL proposal.

Brown: Yes.

Bonney: What went on in those meetings or discussions or whatever they were--talks around the table at night? What were you all trying to do with CIL?

Brown: To do things I don't think we believed--. Well, from what I know now and what I know then, we talked about people locked in back rooms, keeping them out of institutions. I don't think anybody around that table ever met anybody locked in a back room. These were all Cal people. These were all fairly intellectual, hard-working people with good grade point averages and all that. They were not people who had been locked away and unsocialized and had no chances. But that's what we talked about. I didn't really

want to meet any of those people at the time. I thought, "Ick," [laughter] in all truth. I didn't say that; I just thought it. I don't think anybody else did either. We wanted to serve our own kind, I think.

Bonney: You were all focusing more on the immediate community that was there.

Brown: The Berkeley community. The rarefied community of people with disabilities that hung out at Berkeley. They thought they were the center of the world.

Bonney: What groups constituted that community at that point?

Brown: College kids. And maybe a few of what we called "limpers" who lived in the community. We would condescend and be nice to them, but really we were for people who graduated from Berkeley and who had stuff going for them. Not for people who didn't have teeth or looked funny or talked funny. We said we were for them, but we didn't--I didn't really believe that we worked for them. Only in theory.

Bonney: Now was this at the time when you were writing the proposal for CIL?

Brown: Yes. It was for us.

Bonney: So it was for the quads who were coming out of Cal.

Brown: Yes, we had to do something.

Bonney: And it was for the few blind students who were in Cal at the time.

Brown: Oh, there were a lot of us. Blind people always go to school. They may not do anything else, but they go to school.

Bonney: How many blind do you think were attending Cal at that time?

Brown: I don't know. A lot. Thirty? Forty?

Bonney: Were most of those people part of the NFB?

Brown: Probably not. They just did their stuff.

Bonney: How many of you formed this student NFB group?

Brown: There was me, and there was David and Carolyn Cathcart and Dick Santos--he wasn't a student but he was in it.

Bonney: Who was Carolyn Cathcart?

Brown: She worked for something at the time called Determined Productions. They made Snoopy figures or something. She typed. Patty Wright--then she was Patty Finnegan--and I think she may have become Patty somebody else. A real decent person. And Dick's then wife Jan Santos. That's about it that I can remember. Oh--this is early days? Pre-CIL?

Bonney: Pre-CIL, yes.

Brown: Okay, that's about it.

Bonney: What was your role in writing the CIL proposal?

Brown: I was just there. I don't think I had a big role. I think I thought I did, but I don't think I did.

Bonney: What did you think you were doing? [laughs]

Brown: Blazing a path for truth and justice and goodness and trying to write myself a job in there.

Bonney: What happened when the proposal came through and CIL started?

Brown: We were excited, we were astounded. We thought we were going to be able to do great things. It was really exciting.

Life as an Employee at the Center for Independent Living, 1972-1976

Bonney: What was your first job at CIL?

Brown: I was editor of the Independent. That's all I did at CIL.

Bonney: That was in '72?

Brown: In '72 I was part time and then I went full time--for CIL anyway--after I turned in my thesis, which was November '72.

Bonney: What was the Independent?

Brown: We thought of it as a new voice for the disabled and blind; that's what the masthead said. We saw it as writing real articles--not just pushing the paralyzed veterans or--. We wanted to have real

informative articles about whatever on the cutting edge of the disability movement. We always wanted there to be a column about welfare stuff, and we wanted there to be articles on whatever we thought was interesting.

Bonney: How much leeway did you have in determining the content?

Brown: All of it [laughs].

Bonney: So if you didn't like it, it didn't get in.

Brown: Oh, I worked with Ken Okuno and George Howson later, and Ken Stein too. They did a lot of it too. It wasn't just "Jan says."

Bonney: You were editor of the Independent until when?

Brown: Until I left.

Bonney: Which was in '76?

Brown: Yes. I left right after the big administration-goes-on-strike thing.

Bonney: Tell me about that.

Brown: As best as I remember, and I don't remember very well, there was a big scene--or I thought it was a big scene at the time. The administration didn't get what it wanted--and I can't remember what it wanted--but it didn't get it. So it went on strike. Oh, aside from editing the Independent I was their PR person. So I did a lot of press conferences and things like that. They issued their own press conference, a statement, about whatever it was that they were mad at us about. I said, "Administrations don't strike. You guys have the power. I'm the PR person around here." They said, "Yeah, we don't care," basically. So I said, "You know, I'm sick of this place. I'm gone. Lay me off so I can get unemployment." They did.

Bonney: The administration struck against whom?

Brown: I don't know. I guess the board. It may have just struck [laughter]. I don't remember. I don't remember why I thought it was such a big deal at the time, but I thought it was.

Bonney: Who was the administration?

Brown: It was Ed [Roberts] and Judy [Heumann].

Bonney: And did they strike?

Brown: Yes, a day or two.

Bonney: What happened?

Brown: Nothing [chuckles]. I quit, that was my thing. You don't have to be here any more. Go do something real.

Bonney: Were you around when CIL first started and Larry Biscamp was the director?

Brown: Yes.

Bonney: Do you know how Larry got selected as the first director?

Brown: Oh, we just picked him. "Why don't you do it?" He was a community person, as we defined it back then, which meant he wasn't a Cal grad. Why you couldn't be a community person and a Cal grad I'm not sure, but back then you couldn't. Phil [Draper] was a community person, and Don--I don't know if Don Berry graduated. We just picked Larry: "Here, you do it. You're a community person."

Bonney: You really wanted a community person versus a UC person?

Brown: Yes, because this was not PDSP; this was a community agency.

Bonney: What was Larry like as a director?

Brown: He was okay. Kind of laid back and hippie. He smoked too much probably, but that could be said of a lot of people back then. He seemed okay. When the big coup came and Ed was selected, I was out of the loop.

Bonney: Where were you?

Brown: I was there, but I didn't know it was a done deal.

Bonney: What happened? What do you know about that?

Brown: Nothing really, except I was at the board meeting where it happened, and everybody else had been conferred with clearly except me. I fought for Larry. I said, "Wait a minute. Who's this Ed Roberts anyway? He's from Riverside--" or wherever it was. "Larry's from here. Why can't we keep things as they are instead of bringing in transplants? So he's a big deal in Riverside; stay a big deal in Riverside."

Bonney: Did you know he had been at Cal?

Brown: I didn't care. I mean, this was our program, I thought.

Bonney: You say that a lot of people had been clearly talked to before the meeting. Who were those people?

Brown: Chuck Cole, Phil Draper--I don't remember who was on the board any more.

Bonney: So the board just allowed this to happen--

Brown: Sure did. It lobbied for it and it happened.

Bonney: With no real just cause against Larry? He hadn't been doing a bad job or--

Brown: No, no, not really. As good a job as anyone's going to do in these kind of community agencies, which isn't very good. But it wasn't very bad either. What later came to light about Larry's personal life had not come to light.

Bonney: What was it like working under Ed?

Brown: I didn't like it.

Bonney: Why not?

Brown: He was a hustler. He used one grant fund to pay off another, like people do when they don't run an agency very well. He was a politician, he was good at what he did. Fairly grandiose.

Bonney: Was he effective?

Brown: He was effective in getting himself promoted to being head of Rehab [California State Department of Rehabilitation]. He did not run a good center.

Bonney: What was he lacking?

Brown: Interest in what we were actually doing. He had his eye on the goal of Berkeley today, the world tomorrow. Well, Berkeley today could go hang, and the world tomorrow is what was more important. He was not a client services kind of guy.

Bonney: Where was his focus?

Brown: Empire.

Bonney: Just anywhere but internally?

Brown: Empire building.

Bonney: Did you ever interact with him while he was at DR? Do you know what kind of a director he was there?

Brown: I talked to people who couldn't stand him. He gave favoritism to his buddies and bought vans for everybody and spent the budget. But that's just what I heard, because by then I was out.

Bonney: Did you ever work under Phil Draper?

Brown: Yes.

Bonney: How was working for Phil? What was he like?

Brown: He was a nice guy in a difficult position.

Bonney: What position was he in?

Brown: It's difficult to run an agency. It was pretty strange back then in the early seventies. It was a pretty weird place because everybody believed in their own rightness under the exclusion of anyone else's rightness.

Bonney: What do you mean by rightness?

Brown: Their point of view--whether we have dogs in this agency or whether we don't, whether we have smoking or whether we don't. Whatever the issue of the moment might be, most people had inflexible points of view. We went to a retreat, a very bizarre retreat for two days with this facilitator named George Pransky. This was during the Ed time, I guess. What we ended up doing was we were all angry at Ed for treating the staff bad and not making payroll. "Which one of you can go short this week?" That sort of thing. We ended up beating up this not very good facilitator, basically, and feeling a lot better. This guy wept; it was awful. It was terrible. And someone stole our chemical toilet, but we went to the whole enterprise.

Bonney: You made the facilitator cry?

Brown: Yes [laughter].

Bonney: Tell me about not making the payroll. What was that all about?

Brown: It happened a lot. "We're short money. Who can spare it this week?"

Bonney: Would people volunteer?

Brown: Oh, yes. You were supposed to volunteer to show your loyalty to the movement.

Bonney: What happened if you couldn't be loyal that week?

Brown: If you just didn't have enough--you just weren't good enough, were you?

Bonney: So if you couldn't spare not getting paid for the week did you not get paid anyway or did you actually get paid?

Brown: I don't know. I always volunteered it. I never tested it.

Bonney: What made people stay there under those--why did people continue to work there?

Brown: I don't know [laughter]. Feeling maybe they couldn't get another job. CIL was classified at one point as a sheltered workshop.

Bonney: By DR?

Brown: Yes, I guess. Some people felt that their life was the movement. I left because I wanted to find out what life was like outside the world of disability. Is there a world? Could I do something other than this? God, I hope so. Or is all the work world like CIL? I hope not. Everything was a matter of controversy. There was always an issue.

Bonney: Would one get resolved and then another one would pop up?

Brown: Of course. It was awful.

Bonney: What were some of the other issues?

Brown: Smoking. This woman in research and development--I don't know what they did in research and development except hire people--smoking was one of them. Dogs on the premises--

Bonney: Seeing-eye dogs?

Brown: No, pet dogs. What else? Who was going to clean up this dump? "Not me. I'm a quad." "Well, so?" Coalition. Quads have too much power. "Yes, we like it that way; see if we care." It was

just one issue after another, and we were all young adult types. Money--who gets paid more. It was always something.

Bonney: Let's talk a little bit about the quad-dominated--. CIL eventually became an organization that represented more than just people with mobility impairments.

Brown: Sure--not very well.

Bonney: What were the fights over branching out and coalition building and who were they trying to reach out to first?

Brown: People with mental disabilities.

Bonney: Why was that a target population?

Brown: Because there were a lot of them [chuckles]. I don't remember. And deaf people because they were cool. Deaf language was pretty.

Bonney: Was it a genuine effort?

Brown: No, I don't think so. I mean, sort of. It didn't have a feel of genuineness. I'm burnt out on CIL.

Bonney: At that point?

Brown: I wouldn't go to work there now if you paid me.

Bonney: But at that time were there people within CIL who really wanted to coalition build?

Brown: Yes, there were. I don't have enough life experience to know why we should coalition build and with whom, except that if we did it with blind people we ought to do it with other people and that we ought not to water it down too much or nobody would get anything.

Bonney: Were services--

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Bonney: In this time period in the early to mid-seventies, we were talking about coalition building, what I'm wondering is if there was this genuine understanding of the need to coalition build.

Brown: Part of it was also about money. Yes, there was need to coalition build, and different people had different money that came with them.

Bonney: So was it a matter of searching for the services that would bring in the right people, to bring in the right dollars?

Brown: I think we looked for the people and then tried to figure out what services they needed because they were the consumers. And since it was consumer driven--or said it was--they had to figure out what services they needed. We weren't experts in mental health or whatever. We couldn't say that you need a this or a that.

Bonney: Were there experts in mental health on the staff?

Brown: Oh, no.

Bonney: Then how did these people get served?

Brown: They didn't very well.

Bonney: What did CIL do with them?

Brown: Not much. They came through and we could do welfare stuff--I mean, benefits. We could help people find housing. I don't know if they ever did that well or not. We could help people find attendants if they needed them. The basic core services we could provide to anybody.

Bonney: How was CIL at providing specific disability related services?

Brown: At the time it repaired wheelchairs pretty well.

Bonney: What did it do for people who were deaf?

Brown: Nothing other than the core stuff--housing, welfare.

Bonney: Were there race problems?

Brown: I don't know whether they were race or personality. It was predominantly white at the time. There were a couple of Asian people, there was a black guy who I thought was a trip and a half. He lives in Washington and he has worked for Marion Barry [Mayor Marion S. Barry, Jr.] for a long time. He's his own weird self.

Bonney: Who is this person?

Brown: Don Galloway. I liked him. I'm not sure why, but I did.

Bonney: There was a group that called themselves the FBI: Fine, Black, and Intelligent. They were at CIL in this time period.

Brown: They were? I missed them.

Bonney: They had an article or two in some of the in-house newsletters.

Brown: Not while I was there they didn't. I don't think.

Bonney: I don't know the exact dates, but they were talking about being classified at the same level and there wasn't a lot of upward mobility.

Brown: There wasn't for anybody.

Bonney: What was it like there for most people?

Brown: Kind of grim. You did what you did and you didn't get paid and you weren't sure whether you were going to get paid, and there was nowhere to go--up, I mean.

Bonney: Did you do some work for the meetings for the 504 regs?

Brown: No, because I was working for the state and I couldn't.

Bonney: I thought you helped work on some--before the regs were--

Brown: Yes. I worked on something, but I don't remember really well what I did.

Bonney: Something about writing comments to OCR [Office of Civil Rights]?

Brown: Yes, we all did that.

Bonney: Tell me about what that was.

Brown: I don't remember well enough. I said they ought to include--I probably talked about to make sure that when curb cuts were mandated they weren't going to take over the whole crosswalk.

Bonney: And why was that important?

Brown: So that blind people could tell where they were. If the curb cuts were taking over the whole crosswalk you might just walk out into the street without knowing it. I talked a lot about transportation, the importance of having lift-equipped buses--I don't remember.

Bonney: Now this was part of what kind of a process that went on with 504?

Brown: Just we all did it.

Bonney: But you gave comments to OCR? What supposedly happened with those comments?

Brown: They went up the chain. We gave them to--was it Dave Huerta? I don't know. I don't mean to be so vague; it was a while back.

Bonney: Did any of the comments that CIL put forth, do you know if any of them were ever incorporated into the final regs?

Brown: Yes, they were.

Bonney: So CIL had some influence then.

Brown: Particularly Hale Zukas, I think. Such a fine writer.

Bonney: What did Hale focus on?

Brown: Transportation. He cut his teeth on transportation because of BART.

Bonney: How did what CIL offered as comments strengthen the regulations?

Brown: Probably without us they wouldn't have been nearly as good as they were, I think. We were a big deal back then, although it was hard to see that at the time. We really were fighting for inclusion in the mainstream of society, and I think if we hadn't been there the regulations would have been much worse.

Job with Fair Employment Practices Commission

Bonney: You said that you were working for the government when the sit-ins and stuff happened, so you couldn't participate?

Brown: No.

Bonney: You didn't go there at all in the evenings or do anything? Observing it?

Brown: I was on probation. I really wanted my job [laughter]. I really did. I didn't want to have to go back to CIL.

Bonney: What job was this?

Brown: Investigator for fair employment and housing [California Fair Employment and Housing Commission]. FEPC [Fair Employment Practices Commission] as they called it at the time.

Bonney: Was that in San Francisco?

Brown: Yes, 30 Van Ness.

Bonney: Did you get the job?

Brown: Yes.

Bonney: How long did you--

Brown: Four years.

Bonney: What did you do?

Brown: I was an investigator. I investigated discrimination complaints and fair employment and housing.

Bonney: Were most of them resolved fairly towards the person with the disability?

Brown: It wasn't disability; it was everything. And no, usually the companies could prove that they could make the records look like whoever it was got fired for whatever reason they said--except on a few cases, which were kind of fun. I got this old woman to be reinstated in a school district because she was a victim of her husband who was a disabled person and a real victimizer. The superintendent, who wasn't much better--the poor woman was just run ragged. Maybe she wasn't a very good teacher, but she might not have been very bad either. I don't know that she did anything to deserve the layoff that they tried to give her, so we got her reinstated. That's probably the best thing I did in that job. She gave me a coffee cake and I worried that it was a bribe [laughter]. She was a home ec teacher; it was a good coffee cake. So I divided it with my driver and I went back to my supervisor who was a former priest and I said, "Ted, I have something to ask you." He said, "Uh-oh. What's wrong?" "I think I might have taken a bribe." "What was it?" [whispers] "It was a coffee cake." "Was it good?" [laughter]

Bonney: I think it was probably okay [laughs].

Brown: Of course it was, but I was so serious about these things.

Employment and Fund-raising Practices and the Center for
Independent Living's Legacy

Bonney: Let's go back to CIL for a minute. How did people get employed there?

Brown: You knew somebody. Or you walked in and you looked really--I don't know. You just knew a friend of a friend of a friend. That's mostly how it happened. It was a pretty little community at the time.

Bonney: Were there hiring policies and personnel policies?

Brown: I think theoretically, yes.

Bonney: Were they followed?

Brown: No [laughs].

Bonney: What about the role of the board of the CIL?

Brown: It was a rubberstamp board, as they usually are.

Bonney: The board must have known at some point about financial problems that CIL was having. What did they do about them?

Brown: Tried to get money from people who had it.

Bonney: Did they ever look internally into the inner workings of CIL?

Brown: Oh, no. Because Ed was Ed; you didn't mess with Ed. It was a rubberstamp board.

Bonney: Were the Friends of CIL in existence when you were there?

Brown: I think they were brought into being about the time I left.

Bonney: How was their role different than the board's? What were they supposed to do?

Brown: Raise money. They tapped us, they lied about where the money was going.

Bonney: How so?

Brown: They said it was going for--I forget what they said it was going for but it ended up being a piece of wall. They just said it was

going to--something to do with Washington. I don't remember. They said it was supposed to go somewhere and it didn't.

Bonney: A piece of CIL's wall?

Brown: Yes.

Bonney: You mean they fixed a part of the building?

Brown: I'm not sure. But whatever it was, it wasn't what it was supposed to be.

Bonney: Now what do you mean "they tapped us"?

Brown: Me and my husband. I got married in there somewhere.

Bonney: You were on the list of potential donors. But they weren't soliciting the money from their own employees? Or did they?

Brown: Yes, sure. Anybody who they thought had over SSI [laughter]. They used to call them "rich crips" or "settlement crips."

Bonney: A "settlement crip" meaning what?

Brown: Somebody who got some kind of insurance settlement.

Bonney: And had a pile of money supposedly sitting--

Brown: Supposedly, yes. Anything over SSI was a pile of money.

Bonney: When you were there did you see the romance between Ed and Cathy Duggan?

Brown: Oh, yes.

Bonney: What happened there?

Brown: I don't know. I tried not to look. We used to call her unfelicitous names. She seemed like somebody who would do what Ed wanted.

Bonney: And that was a negative against her.

Brown: [Utters sound of disgust] It was one of those romances that was very public in that Ed has a girl; we're supposed to cheer now, okay.

Bonney: Why do you think he chose her?

Brown: Because she would do what he said? I don't know. It didn't last all that long.

Bonney: As you look back on it now, what would you say is CIL's legacy?

Brown: Other centers. Starting the whole idea of the center. If CIL would disappear it would be fine because there are other good centers in the world. Like CRI [Community Resources for Independence] in Santa Rosa is an example of a really good center, and they attract competent people, they have real good hiring methods, structured interviews, and all these nice things that you're supposed to have. They follow their own rules. Good people want to work there. They don't pay anything, like any of these other places. Ten dollars an hour is your top--. But nonetheless, CRI is a good place to work. You don't have to believe in the godlike nature of their executive director or anything. You just have to be good at what you're there for.

Bonney: Was loyalty sort of an expected quality in employees at CIL?

Brown: Yes, I think so. Ed told me once that we should have gone to bed together because then we would have gotten along better or something. Oh, please.

Bonney: Had he not heard of sexual harassment? [laughs]

Brown: No, he had not. None of us had.

Professional Life, 1981 to the Present

Bonney: So you left CIL and you went to the FEPC. What else have you been doing?

Brown: Then my husband and I moved to Maine. I got married in '76, moved to Maine in '81, and played music in schools while I was looking for a better job. I worked for state rehab for eight and a half years as an independent living and regular straight old rehab counselor. And that's where I grew up. I learned that I really wanted to work with people--disabled people or otherwise--and that I was actually even good at it. I got rid of my fantasy of being an editor. The whole front-page type thing, cutting-edge reporter. That fantasy wore itself out.

I really wanted to work with people and I learned how to do that at rehab. We had a really wonderful office to work in.

Rehab region three in Augusta, Maine. I discovered family systems theory. I heard about it in the eighties. It made a lot of sense to me because the way people lived was so much more public and visible in Maine than it is here. You see the pockets of poverty; they're everywhere. The house with the clothes--because people go to Goodwill twice a year. They don't have any washers, and they get a ride to Goodwill so they buy a bunch of clothes for the family. When they get too dirty to wear anymore they dump them in the woods. After a while there's a big pile of clothes out in the woods, but you can see it on the road. "We're going to have to shovel pretty soon because the clothes are reaching the second-story windows." And this was real.

And these were the people I worked with, a lot of them. Just before leaving I was hiring a new driver, and we would go into this house in the sticks somewhere to interview this woman. There was a lot of dog poop in various stages--it was anything from fresh to dried out--and after we got out of there this guy said--and he was a guy who was in alcohol recovery, so he had seen a lot of things--he said, "Bleah! How can people live like this?" This is what scared me--my response was, "They get used to it. This is normal. This is how people live." And the other half of me that was listening to myself say this said, "No, it isn't. No, it isn't. You're headed down burnout road."

We left because my husband was having difficulty with the winters. It was a very hard place to leave, because of friends and music. I was in a contra dance band, and the church that I was involved with. They had a big goodbye party for us in the parish hall. All these musicians came, and friends from all different spheres. It was a small town.

Bonney: What kind of music are you into?

Brown: Celtic. Old-time American.

Bonney: What do you play?

Brown: Mandolin.

Bonney: Where did you go after you left Maine?

Brown: Back here. I thought I would go to therapy school. I thought about being a licensed clinical social worker for a number of years. There were two schools I could have gone to in Maine but I didn't because I was working. I thought, Okay, this is my chance. So that's what I'm doing.

Bonney: Where are you going?

Brown: Holy Names.

Bonney: In Oakland? So you went full circle.

Brown: Yes.

Bonney: And you're studying--

Brown: Counseling psychology.

Bonney: And when will you get through with that?

Brown: In a year from May.

Bonney: What do you hope to do then?

Brown: Work with kids--in a school, I hope.

Bonney: What age?

Brown: Little ones. Like elementary school or adolescents.

Bonney: Tell me, Jan, what has your life been like as a disabled person?

Brown: I don't know how to answer that. I am a disabled person, and that's sort of a pivotal--. I've been discriminated against a bunch. But everybody has; it's nothing unique to me. For example, I applied for an internship at Marin Family Services at the suicide prevention place. And this guy said on the phone, "Is it true you're, um, totally blind?" I let a little silence happen and said, "Yes [in casual tone]." More silence. "Oh. Well, um, how would you do notes?" "On the computer?" And a bunch of "how would you's". So he had to interview me. He was clearly uncomfortable doing that. There were a bunch of stupid questions like that in the interview and then he went to the structured part, which was the appalling part. They asked questions like, "Are you married? Do you have children?" I felt like saying, "Kiddo, these are illegal questions. Don't even--."

Bonney: Why were they even asking?

Brown: Because they're stupid [laughter]. I don't know. No flattering explanation. But I've been lucky in that I've been able to have a job for the most part. The rehab job was a good one; it paid well, it had good benefits. Back here, I don't know. I worked for CRI for a year and a half.

Bonney: Which CRI?

Brown: It's the independent living center in Santa Rosa. The good one. I was their peer support coordinator. That was fun because I got to train up a bunch of peer support workers the way I wanted to train them. It was a lot of fun, and I still am friends with some of these guys. We had a good group and we saw a lot of people. It was a fun job. It didn't pay much.

Bonney: How did you want to train them?

Brown: I taught them about grief, loss, and separation. We had clinicians come in and teach various segments. We talked about suicide, about death and loss, substances. I asked them to go to AA [Alcoholics Anonymous] meetings or a twelve-step meeting of their choice. And if they didn't go that brought up issues for me: "Well, why not?" I'd bring in various presenters and for the most part they were really good and they would come back.

Bonney: How was this different from what a normal training would have been?

Brown: It wasn't; it's just that I got to design it. It was fun. I liked it. I got to design it and teach part of it.

Reflections on the Independent Living Movement

Bonney: Why do you think that the people who made up the independent living movement in the Berkeley area--why do you think these people got involved? Why did they make it happen?

Brown: Because they were a bunch of high achievers and they wouldn't take no for an answer, maybe. I think it was pretty true of most of them. We all happened into the independent living movement at the same time and place. I think that's what happened.

Bonney: Did you realize that it was a movement at the time?

Brown: Some people like Ed probably did; I didn't. I was clueless [chuckles]. I thought, "Oh, that's good," but I never thought of it as being the world tomorrow, the thing we were doing here, until I realized that this could be applied to other places. But I wasn't thinking like that.

Bonney: When did you become aware that it was a civil rights issue?

- Brown: I knew it was a civil rights issue right away, but I don't think I thought of its national applicability until the middle of '73.
- Bonney: Were you influenced by other movements that were going on at the time? Which?
- Brown: Sure, all of them. The civil rights one and the anti-war one.
- Bonney: How did they affect you?
- Brown: They gave me a mindset to question authority and do what's right. The civil rights people did what was right and they went down fighting for what they believed in, and I thought it was a good thing to do. So it had some romance in it. It wasn't just like going and getting your MBA and going off to punch in and do whatever; it had more zing, a purpose to your job other than just money. Please. We thought money was below contempt, although we wanted it. At least I did.
- Bonney: Some people have postulated a theory that people with disabilities are afraid of money and don't really know how to make it work for them.
- Brown: That's odd.
- Bonney: Do you have that feeling or understanding--
- Brown: Afraid of money?
- Bonney: Lots of money. Like as a movement we don't know how to use money to make more money, to help us get where we want to go.
- Brown: We're no good at business? Is that what you mean? I'm not. I'm no good at business.
- Bonney: We don't know how to invest well. We know how to stick our hands out to the feds for more money.
- Brown: We can take but we don't know how to grow?
- Bonney: We don't know how to make it grow for ourselves, to increase it or how to use it to our benefit--
- Brown: We know how to spend it though, right? [laughter] I don't know. It's sort of categorical. I would never hire me to run a business.

The principal of my elementary school, Sister Mark--it's St. Charles school in the Mission, in the city--this woman is my mentor at the moment. She's an incredible woman. She's from the Philippines. She's a pretty tough achiever too. Somebody gave her a small amount of money for her own purposes. You can't own very much as a nun in this particular order. They still wear habits and stuff. She said, "I can't keep this money because this particular family is almost homeless and they need the food." See, I admire that; that's wonderful. She did the right thing.

Bonney: What is the meaning of independent living to you?

Brown: Doing as much as you can do. If you can't do it, find a way to get it done.

Bonney: What have you had to do in your life to get things done?

Brown: I have to pay a driver to get me to and from school, from Holy Names, because there's no way on earth to get there from here. Period. There isn't. Logistically, what I do is take paratransit into the city. No, I carpool in and take paratransit back because it avoids a three-transfer ride. I don't want to hang around in the Mission at the bus stop at eight o'clock at night.

Just getting internships, getting jobs, is a big deal. I have to always tell them, "Oh, no, there will no problem with getting there," and you have no clue how to get there. You have to figure it out, and you do. Because what's the choice?

Bonney: Thank you, Jan. I think that's about it for questions that I had for you.

More Thoughts on the Center for Independent Living

Brown: Joan Leon was part of this whole strike thing, about whatever it was. I can't remember what her title was, but she came in and--I guess she's good, she must be a good fundraiser or whatever she does at WID [World Institute on Disability].

Anyway, she wanted to run my Independent and I said I didn't want her to. It was turf-ish, and also she didn't have a disability; I didn't see why she ought to be running something that I was doing, thank you very much [chuckles]. That was basically it. We called her Phony Joanie and Ed's Kiss-Up--maybe

that wasn't the term we used. She was Ed's yesman, and that seemed like a dangerous thing to me.

Bonney: Did you ever work at WID or with WID?

Brown: God, no. I figured that was a place where old CIL'ers went to die. I never could figure out what they really did. Something about helping people in poor countries. I think they collected salaries. I don't know what they do.

Bonney: I didn't ask you--did you work with Judy Heumann while you were at CIL?

Brown: Oh, yes. "McEwen!" She'd yell at me. [in a tired voice] "Yes, Judy, what do you want?"

Bonney: What were your interactions with her?

Brown: Brusque!

Bonney: Because?

Brown: Because that's just how she is. All a bunch of personalities grating off one another.

Bonney: What kinds of activities was Judy involved in?

Brown: Everything she could stick her fingers in--I don't know. Washington stuff. Mostly national political. I guess she got into lesbian stuff later. But not then.

Bonney: Why in your opinion was she never the director of CIL?

Brown: Because she wasn't a community person. She really was--when she and Phil were running it, she really ran it.

Bonney: But she didn't have the title; he did.

Brown: No, she just told Phil what to do.

Bonney: Was it deliberate that he was the head and she was the deputy?

Brown: Yes. Because he was a community person. She was a college person, I guess. She was a mover and a shaker, so she couldn't be a community person. I think. Then the people I don't want to leave out were John Baker and Gary Gill, who were blind friends. John Baker now lives in Fremont. He used to fix tape recorders and stuff. He was real good at it.

Bonney: What did he do at CIL?

Brown: Blind services, I think. He fixed tape recorders for anybody.

Bonney: And Gary?

Brown: Oh, he just hung around. People did that a lot.

Bonney: He didn't work at CIL?

Brown: No, I don't think so. And there was Jeff Moyer, who wasn't a particular friend; he was just there. I saw him in Maine singing his disability rights songs.

Bonney: You're shaking your head [chuckles].

Brown: I thought they were awful. Attack dogs for the blind. They weren't funny, and I thought they were poorly written.

Bonney: Are they written as satire?

Brown: Yes. They're heavy-handed satire. And Eric Dibner showed up in Maine at Alpha One.

Bonney: That's right; he was in Maine for a while.

Brown: I said, "What are you doing here?" He said, "I don't know. What are you doing here?"

Bonney: Okay, thank you very much, Jan.

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BUILDERS AND SUSTAINERS OF THE INDEPENDENT LIVING MOVEMENT IN BERKELEY
VOLUME IV

Phil Chavez

PEER COUNSELOR AT THE CENTER FOR INDEPENDENT LIVING, 1970s-1990s

An Interview Conducted by
Graham Johnson
in 1997

TABLE OF CONTENTS--Phil Chavez

INTERVIEW HISTORY	31
BIOGRAPHICAL INFORMATION	32
Childhood and Diving Accident, 1970	33
One-on-One Schooling	34
Learning from Other People with Disabilities	36
Attendants Key to Independent Living	37
Physically Disabled Students' Program and Student Life, 1973	39
Cowell Hospital Program	41
Substance Abuse and Wild Times	42
Antioch College West	47
Center for Independent Living Peer Counseling Demonstration Grant, 1978	49
Advocacy Versus Services	56
San Francisco 504 Sit-in	58
Lobbying in Sacramento, Utilizing the Media	61
Disabled Students' Union	64
Future Needs	65

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(Please write clearly. Use black ink.)

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INTERVIEW WITH PHIL CHAVEZ

Childhood and Diving Accident, 1970[Interview 1: March 24, 1997]##¹

Johnson: This is Graham Johnson interviewing Phil Chavez at his home in Berkeley. Phil, could you, first of all, give us a little bit of background of you before you came to Berkeley?

Chavez: Before I came to Berkeley? Before my accident?

Johnson: Yes.

Chavez: I was born in Berkeley but I was living in San Pablo and then in Richmond, which is just north of here. I come from a large family. I have two older brothers, two younger brothers, a younger sister, and now two half brothers and a half sister, but at that time it was the five of us boys and one younger sister. Before, just going to school, doing normal kind of school things.

I was a very active person in terms of very physically active. I wasn't really into organized sports because I was kind of a rebellious type. Sort of when the three o'clock bell rang, I always felt like that was my time. So I never was very into sports because you had to go to practice, but I was very athletic. I was into water skiing and swimming--a lot of aquatic things--as well as mountain climbing or just free climbing. I also grew up hunting and fishing, so from the time I was knee high I was carrying a gun and a fishing pole and tagging along after my older brothers and father in all parts of northern California and southern Oregon--everything from quail and pheasant and duck and geese to deer hunting. A lot of fishing all over, too, as well as out in the bay and in the ocean, so a very active outdoor life.

¹This symbol indicates that a tape or tape segment has begun or ended. A guide to the tapes follows the transcript.

I mean, most of my time, I would say, when I wasn't in school, I was outdoors. I did very little indoor activity. I did get into reading somewhat as my mother read a lot, but mostly did a lot of outdoor fast things. Where I grew up socially, Richmond was a very car-oriented town, so fast cars was a very common thing. Something you strived for was to have a fast car. It was sort of a status symbol.

Getting to the accident part, I'd had probably a number of other accidents before that accident. One when I was diving out of a tree and I hit a submerged log with my shoulder. If that would have been four inches over, I would have broken my neck or died then. I had a couple of pretty serious water skiing accidents. It was pretty common in my family, in general, with five boys.

I don't know if it was something in our blood, or what, but my father used to race motorcycles professionally and I had an uncle who raced motorcycles professionally. I don't know. Speed is sort of in that side of the family. Speed and sort of a wildness in general.

So the weekend, the Saturday that I went to the swimming hole where I broke my neck, I actually had two choices. One was to go with one set of friends water skiing and the other was to go with another set of friends and my girlfriend to the swimming hole. I actually wanted to water ski, [laughs] but we ended up going to this other place where I dove off this little bridge and broke my neck, so that's kind of a brief background on that.

Johnson: How old were you then?

Chavez: I was sixteen. Let's see, it was June 28 when I actually broke my neck and my birthday is August 1, so I was sixteen and turned seventeen in the hospital. Yes.

One-on-One Schooling

Johnson: So did you end up in a position where you missed your senior year of school?

Chavez: Yes. It was the beginning of summer when I broke my neck, between my junior and senior years. That was in some ways probably a positive on an educational level because I was probably just sliding along in school. The Richmond School District was really bad, in general, and I hadn't planned on

taking a lot of college entry courses. I was planning on getting a job either through my father's business which is a contact lens business, or something else, but I wasn't really gearing myself towards going to college.

But after I broke my neck and was at rehab at Kaiser Hospital in Vallejo, the system they had there was a one-to-one teaching situation. They had one teacher for the whole rehab unit and I'd never had an experience like that before. So all of a sudden instead of taking Cooking for Two, which is one of the things I was going to take in my senior year at Richmond High, and two hours of woodworking and a lot of fun things, I ended up taking advanced algebra, history, and advanced English, name it, you know. I mean, every class I had was a work class, a study class.

I'd never had the experience of one-to-one, just a student and the teacher, and it was really quite amazing to me. Throughout, I mean, even though I was feeling pretty overwhelmed by the disability part of it and everything else that was going on in my life--and we'll probably get into that a little bit--that was really amazing to me, the content of how much I could soak in. So because of that, all my grades in my senior year, the lowest that I got was a B in, I think, one or two classes. The rest were A's, which allowed me to--my GPA went up high enough that I was able to get into Berkeley--UCB.

Johnson: So not only did your grades get high, I'm making the assumption that your interest was piqued in terms of education?

Chavez: To a certain extent, yes. I mean, I think I was always interested in learning, but I was never very interested in learning in a traditional fashion. I always kind of rebelled against the school format--the traditional school format--so in high school, especially in my junior year, that's when my grades really dipped for two reasons: I met my first wife, and I just really didn't like the structure of the way things were being taught. I didn't think they were being taught well and there were a couple of my teachers [laughs] I just really out and out hated. So I cut a lot of school, probably spending as much time at my girlfriend's school, which was in Pinole, as mine. I would hitchhike. I'd just cut school and hitchhike out to her school and hang out there.

But this one-to-one teaching experience was really positive. And then after I did get out of the actual hospital, I hadn't quite finished enough credit so I had a little bit more one-to-one tutoring to get my high school degree--just a little bit of that. Most of it was at the actual rehab.

Johnson: What year would this be?

Chavez: That was 1970.

Johnson: And you entered Berkeley--

Chavez: In spring of '73.

Learning from Other People with Disabilities

Johnson: What were you doing between '70 and '73?

Chavez: '70 and '73. Well, it was actually kind of an active time in that 1970 I broke my neck, got married, and we had a child, all in that year. Well, that's not true, the child was born in '71, February 25, to be exact. I mean, I'm trying to learn how to cope with my disability.

One of the things that was probably the real spark more than anything else was I didn't feel like I was getting much of any education related to my disability except how to fix it--in terms of how to fix me physically. No education about how to deal with my sexuality, or my inability to do things in a traditional fashion, nothing around self image, or body image. The sort of model of the rehab was you're only successful if you walked out of there. And maybe 1 percent, 2 percent of the people that would go through the doors would walk out, so they had about a 98 percent failure rate. That was the attitude of the rehab, and I always thought that was really lousy. So that was really the initial spark of what I ended up doing as a career, which is counseling people with disabilities, because I felt like I never really got that the way I needed it except from other people with disabilities at the rehab.

There was one doctor who was pretty good--fair. This teacher was okay, but really just on an educational level, not on a disability educational level, just on a, you know, school educational level. But in terms of learning what I really needed to know and survive with a severe disability--like related to attendants and family and all of that stuff--none of it was taught. I think they've come a little ways since 1970, but it was really bad. That was one of the things that really stuck with me in terms of me picking my course of education later.

Johnson: Were you aware of what was going on in Berkeley relative to student movements?

Chavez: Luckily, I was. A little seed was planted. What it was, was in the bed next to me--we were in four-bed units--and on my left there was a man named Greg Sanders. He had broken his neck a little bit earlier than me, by just a couple of months, I think, in a skiing accident--snow skiing accident--and he was going to UC Berkeley when he broke his neck.

He said that he was going back to Berkeley and I went, "What do you mean you're going back to Berkeley?"

And he's going, "Well, I'm going to go back to school."

I'm like, "Well, what do you mean you could go back to school? You're crippled! You know, you can't go back to school."

And he goes, "No, I'm going to go back and get my college degree."

I'm thinking, This guy's nuts. What's he thinking about? You know? Because there was like no concept, I think, from my point of view.

I saw some people doing some other things, pretty amazing things. There was a paraplegic who had his pilot's license and led a really active life. I got most of my inspiration from other disabled people, which really ties into the whole overall philosophy of the peer model of which CIL [Center for Independent Living] was really all about. The disability movement was really all about disabled people teaching other people and being role models, so really what I learned at rehab, 90 percent of it was from the other disabled people. They had just learned through experience.

So anyway, this man, Greg Sanders, said he was going back to UC Berkeley and that was when I initially heard about UC Berkeley. I had always known about UC Berkeley because I grew up in the Bay Area, but I didn't really know anything beyond that.

Attendants Key to Independent Learning

Chavez: So later, after my wife and I broke up, because it was just really lack of education. I didn't really have proper attendants, my family was taking care of me, her family was taking care of me, she was taking care of me. She was trying to take care of me and the baby. We were trying to make, you know,

a new life, and it just was bound to fail. I mean, there was no way that it was going to survive without a proper support system. And there was no support system. I mean, nobody had told us anything like, "Well, you need attendants; you know, you might want to try looking for a support group, or counseling."

Really the key is attendants. I mean, if I probably would have had two or three good attendants, maybe we'd still be together today, for all I know. I doubt it, but [laughs] it certainly would have helped.

As it is, we probably lasted less than a year before we broke up and she went back to her parents and I went to my mother's home in Richmond. That's where I kind of lounged around for, oh, I don't know, a year and a half or so. I didn't do a whole lot of anything. I spent a lot of time in bed. The house was up about fifteen steps, so just to get in and out, period, I had to be carried.

Then there was actually another Berkeley tie-in. The only place to really get attendants was from Berkeley because there was already this movement started. You know, I kind of had heard little things about it, but nothing really beyond just sort of whispers of this and that. The one thing I did hear was that you could get attendants. This whole concept of attendants had finally come out, so my first attendants were coming from Berkeley--I mean, literally--like bicycling from Berkeley to Richmond. They biked down San Pablo Avenue and worked for me for three or four hours, then bicycled back to Berkeley. One of them anyway. Not all of them. Some of them drove.

But my first three or four attendants were conscientious objectors that didn't want to go to Vietnam, and would come out and work for me for two or three hours. Usually that meant just getting me dressed, getting out. I'd get put into my car and go for a drive, just to get out of the house.

I wasn't even really using a power wheelchair on a regular basis. By 1974 I had a power wheelchair. Not '74, where am I? '72. But it wasn't really practical because I was living in a house with steps and no ramp, and one that I didn't think at the time was even rampable. Since then, just not too many years ago, we finally ramped it so I can finally go visit my mother now [laughs] and get inside the house I grew up in. So the first connection was with these attendants.

So one night, one of my attendants said, "Well, you know, let's do something. Let's go out. I'll take you out and we'll hear some music." I said, "Well, that sounds like fun." You

know, I never got to do things like that, so he took me and we went to this club in Berkeley called the Long Branch. It was down San Pablo Avenue. Commander Cody and Asleep at the Wheel were playing, and we liked them very well, and there was another disabled man there, a paraplegic by the name of Larry Biscamp.

He's a very famous person. I didn't know that at the time--probably he wasn't very famous at the time--but he said some words to me that were very moving and very helpful. At the time it was just kind of funny, but he said, "Where are you living and what are you doing?" I told him, "Well, I'm living in Richmond and there are all these stairs." He said, "Ah, man, that's a drag." He says, "Move to Berkeley. Berkeley's just a bunch of freaks and you'll just be one more of them." [laughs]

Physically Disabled Students' Program and Student Life, 1973

Chavez: That was great because at the time, to be quite honest, it wasn't that funny. It was sort of like, God, who's this guy telling me that Berkeley's a bunch of freaks and come be another freak? But he meant it in a good way, he really did, and so I thought about Berkeley more and more. That seed had been planted and that was really blossoming. I can't remember actually where I'd first heard--probably from Greg Sanders, when I was in rehab--about PDSP, which is the Physically Disabled Students' Program, but I thought, well, you know, I could always check it out at least.

So I got a Department of Rehab counselor and she was really pushing me just to do something, right? She pushed me and pushed me, so I said, "Okay fine, I'll take some tests. You want me to take tests." So I took a whole battery of tests, and when the results came back she said, "You're college material." Just like that. That was the word she used. I said, "Okay," so she told me more about the Physically Disabled Students' Program and that I should go visit it.

So I did. I went to the building on Durant, which was where it was at that time, behind Top Dog, which is still there. That was where the original PDSP was. Actually, I can't say that for sure. There might have been an original building on campus, but I don't know that for sure. You might want to ask somebody even a little older than me, but the original PDSP--to the best of my knowledge--was in this sort of old Victorianish building behind Top Dog on Durant, just off of Telegraph.

It had this terribly steep ramp that was totally non-code [laughs] and a little kitchen, and that's where they operated pretty much everything, from wheelchair repair to attendant referral, and they even had a little bit of counseling. Not much. No, I don't think we had counseling.

But so I saw that. Wasn't too impressed by that, but then when I went over and visited the actual hospital dormitory area, which was at Cowell Memorial Hospital--which is no longer there; it's been torn down--the actual building. That was pretty impressive to see. You know, about ten severely disabled--all male at the time, I think there was one woman, called Judy Taylor, kind of tooling around, all in twelve-volt power wheelchairs, which were half of what we have today; all the chairs today are twenty-four volts--top of this mountain, it seemed like, and going to school. It was like this mind-blower, eye-opener.

It was very enlightening and frightening and scary and everything, but I knew that I needed to get out of Richmond if I was going to do anything with my life. I knew that if I was going to do it, I would have to take that big, huge plunge. I said, "Okay," so a man by the name of Donald Lorence worked really hard to get me into the program.

Because at the time they considered me very high risk--not because of my grades--but because I was a C-4-5 quad, which means my cervical break was at the fourth and fifth level. Well, for 1972-73, that was considered as a high quad. Today a high quad is like Christopher Reeves, you know, C-1, C-2, even C-3 is considered high, but 4-5 isn't even a high quad anymore. Then it was a high quad, so it was my physical condition and also what was going on in my life with my marriage and breakup. All that was sort of somewhat public knowledge. At that time they didn't know if they wanted to take a risk on somebody like me.

I was talking years later with Donald Lorence, who was the director of PDSP for many years, and he said, "Yes, we had to push really hard to advocate for you to get into the program." But once I did get in, I did quite well in terms of managing my power wheelchair. Mostly I took my cue from other disabled people, other people who'd already learned some of the ropes.

It was really difficult. One of the things that was really hard about going to UC Berkeley as a disabled student was no matter where you went on campus, to get back home was up this darn hill. Back then we were in these twelve-volt chairs that had extremely limited range, especially if you were going up and down a hilly campus such as UC Berkeley. It would probably have

been fine if it was really flat and things like curb cuts were the way they are today, but there were no curb cuts at that point. There were a few staggered around, but very few. A lot of places you had to take these very circuitous routes just to get to your class.

Most students could just go, "Okay, well, I want this class, this class, and this class," and sign up for them, and if they got them, great. We had to go, "Well, okay, this class, first of all, number one, is it going to be wheelchair accessible? Number two, is it going to be close enough to my next class so I can strategically get from one place to another?"

All these things had to be taken into consideration, let alone having note-takers and attendants, if they needed to go to class with you. All those kind of things were just really hard, so to carry a full load--you needed to carry twelve units--was really difficult. Even for the brightest students it was not easy because of our really limited wheelchairs and limited support services.

Cowell Hospital Program

Chavez: The support services from PDSP were pretty good, but from the actual university there wasn't much at all. At the facility itself at Cowell, there was a "nurse" on staff, who was actually really a good woman. Her name was Edna Brean, and she was really good.

We bashed heads quite a few times because I would do wild and crazy things. Like one time I asked if I could paint my room because all the rooms were these god-awful hospital colors. Lime green and terrible yellow. It was just awful, so I asked if I could paint my room. It was a big thing. You know, it was like, "Oh, my god, you can't do that," you know.

They said, "Well, it's a hospital, so you have to use enamel paint." So I'm like, "Okay, I'll use enamel paint." I showed them before she left--because she actually left at five--I showed her the main wall I was painting, which was this kind of nice pastel blue, you know, a nice serene color. She saw that and she kind of calmed down and went, "Okay," but she didn't realize I had four shades of blue, bright orange, and a very bright gold. I did all the window trims in this bright gold, the door frames in bright orange. The one sort of serene blue wall went into this darker blue wall and then this really dark, dark, almost

royal blue wall. [laughs] So you walk in this room and it's just like it jumps out at you with colors. [laughter]

So that night I had to sleep in another room because of the paint smell, especially with all this enamel paint. So when Edna Brean came in the next morning, I could hear her all the way down the hall. She went, "Where's Phil Chavez? Where's Phil Chavez," just screaming at the top of her lungs. She took one look at the room and just flipped out. Then it became this whole thing, this big to-do, and like whether they were going to kick me out or not because I painted my room too bright.

The painting of my room incident at Cowell, that was [laughs] an event, but Cowell Hospital was pretty wild in those days. I mean the college--the dormitories--you think, Oh, yes, it's pretty wild anyway when you think of things like Animal House or something. It was a wild time.

Substance Abuse and Wild Times

Chavez: That's one thing that doesn't get talked about a lot in disability history: how much substance abuse and stuff was going on, how many prescription medications you were taking, how much drinking was going on, how much acid was being dropped, how much pot was being smoked, and things like that. It seems always to be left out of histories when the reality is everybody, from the most important people--from Ed Roberts--all the way down the line were very involved in that part of the culture.

It seems to always get kind of left out of the history, [laughter] so I'm going to just throw it in there because it was, I think, a very important part. People don't realize a lot of these great ideas came after two or three joints. [laughter] You know? I mean, I'll tell you, I can remember living up at Cowell Hospital and tooling all the way down, which then was a long ways, in a twelve-volt wheelchair, from the top of Cowell Hospital all the way down to Ward Street, which is where Ed Roberts lived, on Ward Street, and getting very, very stoned, drinking good wine, smoking very good marijuana, and thinking of great ideas about how we could change this, where we could put a curb cut, or what we could do next. That's kind of always left out.

It seems like whenever I read anything about disability history nobody ever mentions that. They always are afraid to

talk about the fact that there were a lot of potheads and stoners, and a lot of acid.

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Johnson: So let's talk some more about the wild things. Is it personally that might have been part of the way you were trying to make your existence normal as opposed to the way of being viewed by the rest of society?

Chavez: Well, I think it was, and I think it was also a way for the disabled people to get together and socialize. You know, because Cowell Hospital itself was very isolated. I mean, we were at the top of the mountain, literally. We were across from the football stadium, which is way up there. We couldn't just sort of casually say, "Well, let's go out for a beer." You know, I mean, if you were going to do something like go to Telegraph Avenue, that was an adventure. Yes, I mean, anything where you left the hospital was an adventure.

Being also isolated at the hospital, you were kind of stuck there for a lot of hours; and kind of stuck in that kind of situation with ten, twelve other people, it's pretty natural that you're going to end up, you know, drinking or partying or whatever. I mean, you're not going to study all the time, and we didn't. I think partying was a big part of the socializing that went on. We would also have these big dinners, I remember, where we'd have this outside cook come in and cook for the students, and that was a real social part of it.

There were some of the early experiences of poker games at the first CIL which was on Haste Street. I happened to be dating a woman that lived in the same building and so I would often go over and frequent these poker games, or we would have poker games at her house or parties or whatever.

But partying was a very big part of that whole time; it wasn't just us as disabled students. I mean the early and mid-seventies period was just a very open kind of period--not just drugs and partying, but very open sexually, too--and so disabled people were really exploring those boundaries as well. I mean, a lot of relationships and things were going on in that way, and that was very eye-opening for me. I was always very much into the opposite sex, and there was a lot of dating between attendants and people they worked for, and vice versa with attendants and attendants and disabled people and disabled people, and it was a very active time.

What was interesting then, as compared to now, is that it was a very tight-knit group. It was like every disabled person knew every other disabled person in Berkeley, I mean, if they were involved at all in the community. There might have been disabled people that were shut-in that lived here all their whole lives, but you usually always knew about the disabled person before they even got to Berkeley. You know, the grapevine was so fast and swift that you'd hear about so and so coming in from-- this one guy from Hollywood--he was supposedly this movie director.

He didn't last long. That was the other thing. People would come to Berkeley and if they couldn't cut the grade in terms of handling social pressure as well as school, living on your own and just all the pressures that went with this new frontier or whatever you want to call it, a lot of them didn't make it. They'd come to town, maybe last six weeks or whatever, and they were back to Ohio or southern California or wherever it was, because it was too scary, it was too much. It was a lot to deal with. You had a lot of pressure to be accepted into the disability community, you had a lot of pressure to make it scholastically, there was a lot going on, and a lot of people didn't make it. You'd see that quite a bit.

Johnson: So there was a lot of pressure sort of politically, meaning to be politically active in the cause to get disabled students their rights as any other student on the campus would have?

Chavez: No. I wouldn't say so. I wouldn't say it was that kind of pressure. Not within the disability community. There wasn't that much peer pressure on other people to say, "Okay, well, you know, if you're going to be part of the community, then you have to be politically active." There was some of that, but it wasn't like you were ostracized if you didn't. I wouldn't say there was that kind of pressure, but I think you were more accepted probably if you did get involved.

But most of the people that came to Berkeley wanted to get involved. The atmosphere was ripe for that, and it was very rare when someone didn't. And maybe in that sense there was pressure, and they didn't feel accepted and so people probably would leave.

I can remember this one person, in particular--I won't use a name--but who did come up from Los Angeles or Hollywood, as the way he is known by his reputation, and he was very flamboyant and he was supposedly somehow connected to the Hollywood industry. He just didn't cut it. His bullshit didn't fly with the disabled community. We were into making change, we weren't very much into

image back then. That didn't impress anybody, so he came up, didn't impress anybody.

He took a bunch of us out to dinner one night at a very fancy restaurant. I remember him specifically ordering the best champagne the place had, and a friend of mine catching the waiter verbally and with eye contact, and saying do you have any Korbel, knowing that this restaurant's best champagne probably cost about \$100 a bottle. \$100 bottle back then was a lot, you know, for a bottle of Dom Perignon, or whatever it was. It was just a really funny story because here was a bunch of cripples around a table at this real fancy restaurant and this guy trying to put on this big show, ordering the best champagne. Then the check came around and not only did he not pick up the check, but he didn't pay for his own bill. Like I say, he didn't last. He didn't hold up to the pressure. He started actually hitting the bottle really hard, which a lot of people did.

It's not talked about a lot, but a lot of people drank heavily and took a lot of prescription medication, or did both. Some of them didn't make it. Some of them did. It's amazing to me when I really stop and think about it, how strong those initial people that went through--especially through the Cowell dormitory program before it moved off campus--what survivors they were.

A lot of them have died from various things, but the ones that haven't are still around. I think of names like Don Johnson and Bob Davis, and myself and Tom Lyndstrom. I was in one room, the first room, if you were walking down the main hall of the cripp dormitory. I was in the first room on the right. Bob Davis was in the first room on the left. The second room on the right was Don Johnson. The second one on the left was Tom Lyndstrom. The next room was Michael Pachovas. All of these people are still around. One of them was heavily into alcohol, another one was heavily into downers, another one was very much a pothead, I did a lot of everything, another one was very much into hash and other things. We all did this and went to school and were politically involved. It's one of those things where I really don't care [laughs] if this gets published. It's sort of just not talked about very much, about how much a part drugs and alcohol were part of the overall scene.

But what always amazes me--what I wanted to get back to--is what survivors those original whatever you want to call them, the founders, you know. Some of them were part of the Rolling Quads, some of them were part of PDSP, some of them helped start CIL, some of them you know started other things. But a lot of those people were really amazing in terms of their longevity and their

ability to get through because a lot of them are still around and still active. Just out of the five people that I just previously mentioned, as far as I know, all of them are still alive and are still in Berkeley and still doing pretty well.

Johnson: Now you moved on from Berkeley as a school.

Chavez: Yes.

Johnson: And went to Antioch West.

Chavez: Well, I moved off of campus with another disabled man, Michael Pachovas, with whom I co-founded the Disabled Students' Union at UC Berkeley. He's an amazing guy. He's still quite active--a big, robust guy, a 300-pound Greek--and really a fascinating man. We lived on Ellsworth Street for a while. That was my first experience with really living out on my own, managing all my own attendants, and things like that. I'm trying to think if I was still going to school. I think I probably stopped going to school. It was almost simultaneous in terms of when I moved away from campus and when I stopped going to school because I only went to school for about two years at Berkeley.

I didn't do too much. Oh, that's not true, [laughs] I was on the advisory board of the Disabled Community Health Clinic [DCHC]. I helped start the first emergency attendant program with quite a few other people including Scott Luebking and Cece Weeks, who ironically enough, now twenty years later, is running the city program called Easy Does It, which is the emergency attendant program, emergency services program.

How I got to CIL was we were all doing it volunteer. It got down to just Cece and myself and then Cece dropped out because it was just too much, both of us paraplegics, not really having anybody to do clerical work. So I took the idea to CIL and said, "Look, the community really needs this service, we weren't just doing attendants." They agreed and so I was volunteering there for a while before I was hired on staff as a regular attendant referral counselor. Then later I became the manager of that department.

Then actually, I didn't really like being a manager. Middle management at CIL, in general, was difficult because you had a lot of responsibility and no real authority, no real power, so some of us that were in the direct service would kind of avoid middle management. To this day I've kind of stayed away from middle management at CIL.

Antioch College West

Chavez: I've always liked the direct service contact aspect of working at CIL, which is what I always really wanted to do. So while I was an attendant referral counselor, I heard about this program that was being developed through the University of Antioch that was going to be jointly sponsored by CIL. It sounded really interesting and it was about counseling and stuff that I had thought about all the way back to when I was in rehab, so I looked into the program and thought, Yes, this is really for me.

But I was just going for my undergraduate degree; I'd only been a couple years to Berkeley. But fortunately, they let me in with about four or five other undergraduates and about thirty students that were going for their master's degree. We all went to basically the same classes. There wasn't really a grade system per se, it was just like each class you were evaluated. Antioch was kind of a school without walls where you can tailor your own degree, so I basically tailored my degree specifically in counseling, with a hospital administration minor, towards counseling people with disabilities.

Also, the other beauty of Antioch was that you could document life experience. Well, I had already done so much in terms of my work with the advisory board at the DCHC, some of the stuff I had done through PDSP, and the founding of the Disabled Students' Union, so I was able to document that for credit. So it really helped in terms of getting through school.

So that was good, except when I look back on it, wow, how did I have the energy to do all that? Because, basically, I would get up and do my attendant routine, then I would go to work and work all afternoon until five, then I'd take a quick break and then I'd go to school from five until nine at night. Then I'd get home and study, and you know, do my papers and stuff. I did that for three years.

Johnson: The way you listed that made it sound really easy. Getting to school--you were living in Berkeley and traveling to San Francisco?

Chavez: Well, that was one of the good things about the program was that the classes were all over the place, but most of them were right here in Berkeley. And a lot of them were at CIL. You know, it was kind of a fly by the seat of your pants kind of program, really, and it wasn't really well funded, so it wasn't exactly like there was a campus. Even though there was technically a campus at University of Antioch West, this particular program

really kind of got its teachers, its classrooms, anywhere it could, so a lot of the classes I went to were in trailer buildings at CIL.

We used to have a lot more actual property at CIL, and we had these trailers and a lot of the classes were in these trailers. A lot of classes were at a couple local churches. First Congregational Church is where a lot of our classes were.

A few were in San Francisco at scattered locations, and yes, sometimes it was difficult, especially when the classes were in San Francisco, because that meant taking BART over there which was just time-consuming and tiring, as well. You'd get all the way over there and, you know, it's at night and you're trying to take a class in like something maybe you weren't that interested in. Like I was doing a hospital administration minor, so you're taking these health care administration classes, which to me is really like ugh. I wanted to focus on the nitty gritty counseling stuff of working with people with disabilities, and so that was hard. Yes, it was.

I pulled many all-nighters, you know, where I would usually hire someone. This one woman I remember, in particular, was very good. I would just stay up until all hours of the morning just dictating to her, you know. She'd be writing it down. [laughs] She was my tape recorder, you know, and it was a lot better. I used a tape recorder a lot because I couldn't really write, but it was slow and tedious because then you had to play it back and write it down, whereas if you worked directly with another person, you usually got it down and then could just go back and edit it once and turn it in. So that's the way I did most my papers and most of my assignments.

Then the actual classes, a lot of them we could do orally. That was one of the accommodations. Tests and stuff you usually --most of them I did orally. I'm a fairly vocal oral person anyway, so that was probably to my benefit. Compared to the written word, just different formats were difficult. They don't have Dragon Dictate like I have now so, I mean, if I had had Dragon Dictate then it would have been a lot easier. But also just the nature of the way the school program was designed, it really did facilitate for disability accommodation, you know.

The classes were tailored toward people with disabilities, so that was one of the things that appealed me. I'd always hated traditional school structure anyway, all the way back as far as I can remember, so this is what really appealed to me about this program. It was always called "school without walls" and that really appealed to me. A lot of my evaluations of the classes

that I either documented or I took were done by people I really liked or knew personally. I had some just great classes, some incredible classes.

I think of a man--who's passed away now--probably one of the best classes I ever had in my life was called the physiology of disability, taught by Dr. Sheldon Berrol, a very important man in the overall disability history. Shelley was a great man--a great, great man. Ask anybody who knew this man, and they'll tell you the same thing. A great, wonderful, loving man, and a brilliant man. A doctor, but also a wonderful teacher--just a wonderful teacher. His class was just incredible.

It was taught in this funky little part of CIL underneath the stairway where the accounting office is. That's where we had physiology of disability. That was a great class. We read our textbook from cover to cover, plus some. I learned more in that class about different disabilities and different physiological aspects of them than I ever have in my life, and it was amazing.

So I had some really good teachers. But it was also on a very personal level, and it was totally the opposite of what UC Berkeley was. UC Berkeley was so impersonal--classes would be 300 and 400 people in some of the lecture halls--whereas here usually the biggest classes may be ten people, and usually six or eight, with a teacher that you knew intimately. If you wanted time from him or her, you know, you'd just ask for it. It wasn't like you had to schedule a time during study time once a week; you'd just say, "Hey, do you have a minute?" And talk about whatever it was you were trying to learn. So that was a really positive experience.

Center for Independent Living Peer Counseling Demonstration
Grant, 1978

Chavez: Then when I did graduate, there was another job opening up at CIL that was really tailor-made. The timing was just perfect. It was a research and demonstration project funded out of Washington, D.C., to prove the viability and economic feasibility of peer counseling. That was then in 1977, or that was in like '78. Actually, Ken Stein would know if you wanted the exact dates. That was a pretty bold and innovative concept that disabled people could counsel other disabled people. It's sort of like, "What do you mean? It has to be the traditional mold," so this was like breaking new ground.

It was really effective. It was really, really effective. I helped a lot of people get out of institutions. It was very empowering, not just for the people I worked with but for myself. I mean, to be able to sort of pass on, you know, the kind of knowledge and stuff that I'd learned, but at the same time learn from them as well, you know, so it was a very shared experience.

That's what I've always found about the peer model and the disabled movement is it never was very hierarchical. It wasn't a one-up kind of thing, it was almost always an even basis. I always felt like I could talk with just about anybody, like Ed Roberts is a good example. I mean, just because he was a very approachable person, it didn't matter that he was the head of the Department of Rehab of the State of California. Even then he was pretty approachable. Sometimes he wasn't because he was busy, but if you ran into him in the street, he'd always stop and talk to you. That's kind of the way that the overall movement was in general.

I think later some big egos came into the overall scene and it started being, you know, a lot more in-fighting and political, the way politics is in general. I think some of that was going on in the early stages of CIL, as well. One of the things I'd like to clear up, for the record, is that I think most people you talk to that have any knowledge of CIL at all think that Ed Roberts was the first director. That's just not true. Ed Roberts was not the first director. I'm not even sure who the first director was. I know that Larry Biscamp was the first director to my knowledge, and actually, I remember being on Haste Street at a meeting where he was sort of ousted. He finally said, "Fine, you guys don't want me; I'll quit," and that was it. That was the end of Larry's heading CIL.

But I think it was positive. I think that the way it was done was not great--it was very back-door politics, a few people got together and decided they wanted Ed to be director and kind of pushed it through--and the way it happened I don't think was good, but it happening, I think, overall was good because Ed's vision was much broader than anybody's, period.

I think Ed saw things really globally and saw that this was a much bigger thing than just Berkeley. I think most everybody else was really looking at just Berkeley. We were going to make things better for the disabled people in Berkeley, and not beyond that, but I think Ed really saw way beyond that. I think a few other people did, too, but I think it was Ed who had the original vision.

But the original origins of CIL and stuff, you have to give credit to quite a few other people, I mean, not just CIL but PDSP. I think you have to credit Donald Lorence, who was the director of PDSP for a long time, and Larry Biscamp, who I mentioned before. There were a lot of other people that just sort of go unnoticed: Larry Langdon, who's no longer living; Mary Anne Hiserman, who's no longer living; Greg Sanders, who I mentioned earlier--there were a lot of people--Herb Willsmore, Judy Taylor, Lennis Jones, Hanoi Richey, Michael Pachovas--all these people had something to do with what happened.

And it really snowballed after a while.

[Interview 2: April 7, 1997] ##

Johnson: It appears that the personalized members of the disabled community shaped the political necessities. Political action was needed to level the playing fields so disabled people had the same opportunities to choose their own paths. This leveling took the form of community-based organization such as CIL and political reforms like 504 that recognized the individuals' rights and passed laws to make sure they were not abridged. First, I'd like to explore further your work at CIL and the snowballing of the community-based organization that you talked about when we last spoke.

Chavez: Okay, as I stated, I started working at CIL because I had helped organize the first emergency attendant program. That was strictly volunteer, but when the other folks dropped out of that, it was really left to two of us--two quadraplegics--a woman named Cece Weeks and myself. When she decided not to continue doing it anymore, I thought it was a really important program, so I brought it to the CIL director, at the time, I'm trying to remember who that was--1975--I think it was Phil Draper, but I wouldn't swear to that. I said I would be willing to work on a volunteer basis, whatever, or just asked if I could have some space and some telephones and, you know, office materials to get the emergency attendant list out. Now attendants are referred to as personal assistants. So they agreed that was a very necessary service and so I started working.

I realized in a very short time that the attendant referral department at CIL was overworked and understaffed and so I ended up doing as much emergency work as regular attendant referral counseling, which was basically interviewing potential attendants and matching them up with disabled people in the community who were looking for attendants. So I started doing more and more of that and that's when I actually went on staff, was at the end of 1975, as a regular attendant referral counselor.

Johnson: This was a paid position, now?

Chavez: Yes, it was a paid position. So it was volunteer probably about four months, and then I went paid, I think, in December of '75.

I'm trying to think if I had any other contacts with CIL prior to that. They really go all the way back to when I was first at CIL and first met Judy Heumann, Nancy D'Angelo, and Sandra Thaylor. They were living in an apartment in the same complex where the original CIL apartment was, and since I was actually dating one of the women--dating Nancy--all of our social activities were going on in that complex. I would go over and visit the CIL apartment and kind of sit in on meetings and things like that, so my original contact with CIL goes all the way back to when they were in their original location.

Then as a consumer or client, I remember seeing the original peer counselor, Peter Leech. There's a wonderful photograph here of him at the University [Avenue] office. This was on the second floor and they had to move out of there, I guess that was at the end of '74--sounds about right--because of fire regulations and the elevator and everything. The fire marshall [laughs] didn't want all these people in power wheelchairs and wheelchairs and whatnot in that kind of situation, so that was when they moved to this location, which is 2539 Telegraph.

It used to actually be an old British sports car dealership. It was like Triumphs and MGs and things like that. I remember it well when it was like that.

So I came to CIL and then, ironically--I lived a very short distance from here, so when they moved from University, it was great for me as a client. Then the fact that I was doing a lot of community work, anyway, related to the emergency attendant stuff and other community work related to being on the board of the Disabled Community Health Clinic at Herrick Hospital--now Alta Bates/Herrick campus--and work that I'd been doing at the University of California with the Disabled Students' Program--actually, not just the Disabled Students' Program, but the Disabled Students' Union--that when they moved to CIL, or when CIL moved over here, it was really great for me. When I actually started working here, it was wonderful, too, in the sense that for me it was a five-minute commute to work by chair, or less if I was in a hurry. It was like three minutes after I got a faster chair, at least. But it was really really nice to be able to not have to commute a long distance to work.

So then I became the manager of that department, and sort of got my first taste of middle management at CIL. I realized that

was something I probably never really ever wanted to do in my life again, because it was a lot of responsibility with no real authority. You're kind of stuck between administration and the front line people. I found it to be, you know, very tedious and frustrating and too bureaucratic for me. I really liked working directly with consumers and always have. I think that's what's kept me doing this work for so long. I still really, really get the juice from working directly with consumers.

I guess I haven't really gotten used to using that word. I mean, for twenty years we used the term client, or for nineteen years. Has it been more than twenty years? Just it's a fairly recent historical change in terms of calling clients consumers. I lost my train of thought.

Johnson: You were doing middle management.

Chavez: Middle management.

Johnson: Not enjoying it much.

Chavez: As a matter of fact, one of the things that comes to mind is [laughs] how tough of a crew we were to just manage in general, I mean, in terms of being in a supervisorial role.

As a matter of fact, one of the future directors of CIL was my supervisor. Michael Winter became the director of CIL and this was before he went to Hawaii and was the director of a center in Hawaii. I don't know what his title was. I think it was sort of like what we have now which is services supervisor. That might have been it, I don't know. I just don't remember that well.

But I mean, it was the kind of thing like he would come to our apartment and say, "Okay, well, we're going to have a staff meeting tomorrow at two p.m." and we were like, "Yeah, right. Screw you, Michael. [laughs] We'll be there if we feel like it," you know, kind of thing. That was kind of the attitude we had. We were like a lot of loose cannons in terms of the people who worked here. There were a lot of free spirits and we did our job and we did it really well, actually, but we didn't deal really well with authority on any level--whether it was internal at CIL or external. Sorry. [motor noise]

So I had a little taste of middle management and realized that that was not for me and that I really liked working on the front lines and, at CIL, working with consumers. Part of my job was also doing mediation between attendants and clients that were having difficulties for whatever reason. I didn't do a lot of

that, but it was important. That, I think, is important because that was probably my first real counseling experience. Even though the title was attendant referral counselor, you didn't really do that much counseling per se. You did a lot of practical stuff, but not traditional counseling.

But when I did the mediation, I got more of a taste for counseling and realized that I have a pretty good skill in that area. So later, when the position opened up at CIL for a "peer counselor" it was perfect timing-wise because I had been going to school and tailoring my degree at the University of Antioch West toward specifically counseling people with disabilities. So the timing was perfect to move from being an attendant referral counselor to being a peer counselor where I worked more directly with people who were transitioning from dependent living situations into either semi-independent or completely independent living situations. So that's what I started doing, which was the research and demonstration project at CIL.

I'm trying to think when I started doing that. Was it '78? Yes, it might have been '78, or early '79.

Johnson: Exactly how did that work?

Chavez: Basically you had four independent living skills peer counselors. They were really called peer counselors but I really want to throw in that the term ILS is really important--Independent Living Skills--because that's what we really did. We counseled people on specifically how to utilize independent living skills: everything from basic counseling related to how someone felt about making this kind of move to much more practical things, you know, like how do you find a house, how do you find attendants, how do you find an apartment, how do you deal with a landlord in terms of setting up a lease, how do you get a place ramped, how do you get your benefits. All the things related to survival. You know, how do you get your wheelchair fixed? How do you get a wheelchair if you don't have a wheelchair? How do you get a cane tip if you're blind? Whatever it was, so it was a very case by case situation.

Even though there were a lot of generalized things that we would teach that would cross over, we would try to use the peer model. In terms of if it was, say, another white, spinal cord injury male, then I would usually see them. If it was a black, vision-impaired person, then one of the other counselors who had a similar disability--we would try to match disabilities as often as we could. I mean, that was impossible to do all the time, but that peer model seemed to be an effective way so that the client could look at this other person and say, "Well, they're very much

like me and they're doing it. They're living independently, they're managing their life, so if they can do it, I can do it."

The role modeling was really critical in everything. I mean, you could talk about specifically what we're talking about now in terms of peer counseling for independent living skills, but right across the board to advocacy and political things and everything--that whole thing of seeing another disabled person in a leadership role or, you know, in front of a microphone talking to the media or whatever. It was sort of like, god, if they can do it, then I can do it.

That kind of thing was so critical to the movement in general, and it was so important in terms of peer counseling and independent living philosophy to be able to be a role model. That was really, really valuable, and I know for myself that that's where I learned the most from was from other disabled people. Right from the start--right from when I broke my neck--and was in rehab. The people I really learned from weren't the doctors and nurses and physical therapists and stuff, it was from other disabled people. That's where I really learned. So it was just really carrying on that basic, really base level of, well, if this person can do it, I can do it, too, kind of thing.

But once you get past that, you really have to teach people the skills. If they don't have the actual skills, then you have to, you know, do some hand-holding at first and really walk them through, for lack of a better phrase, the steps of whatever it was. Going and opening up a bank account or something as simple as that. What we would think now is as simple as that would be--could be--really frightening to someone who had never ever handled their own money before. A lot of times we would get people with disabilities that never really dealt with that, either because of their age factor--like they broke their necks maybe at age fifteen and then never experienced having their own bank account and things like that--

A lot of independent living skills were related to money management: dealing with your benefits and living on a very minute fixed income, and you know, finding an apartment. We're still doing that to this day.

It's actually gotten more difficult. The housing situation in Berkeley--the rents are so high now that they don't even match what the benefits are--so a lot of what we did was teach people how to find roommates so they could share expenses. Things like that.

Johnson: How much do you do work with--on the other end of the scale--people who have become disabled at a later age of life, and what sort of differences have you had to work with, with regard to that population?

Chavez: Well, I would say when I first started working at CIL, probably for the first four or five years, I worked with both populations a lot, in terms of people who became disabled later in life or people who were born disabled, but it seemed like I worked a lot more with people who became disabled later in life. I don't know if that was just because that's what happened with me, that I was a traumatic spinal cord injury myself, and it was sort of a peer model or what.

But then later, when I started teaching independent living skills, I started working with a lot more people with cerebral palsy and that's from birth--a lot of different disabilities, actually--but a lot of developmental disabilities from birth. Part of that, I think, was just that population was starting to come out more in general. State hospitals were starting to get a little bit more flexible about releasing people that might be able to live on their own.

In my role as a peer counselor, I started doing much more aggressive advocacy in that kind of area, in terms of going into state hospitals or Fairmont, which is the Alameda county facility, and basically what I called getting people out of jail --which is what ADAPT [American Disabled for Attendant Programs Today] now is all about--the program to get people out of institutions. I mean, that's what we've been about all along, a major part of our role on both a practical level and on an advocacy level.

Advocacy Versus Services

Chavez: One of the things that's interesting is now CIL has come full circle in that we're trying to get back to becoming more of an advocacy organization as opposed to a services organization. I just find that really interesting in that we kind of did get away from our original philosophy and goals. We've always been both, but there's always been that really--well, now you can't really say always, but I would say in the early years--in the seventies and early eighties, the sort of militant advocacy level was a lot stronger. Then, in the later eighties, I felt like that really got lost somewhere on some level. On a national level I think it

kind of picked up momentum, on a local level I feel like it lost something.

We started becoming more of a service agency where people would come to us. There were just little things, like, we started closing at lunch. We used to never be closed at lunch. We were always a nine-to-five organization, but we were always open at lunch. It was very much a gathering place and things like that. We became much more like standard agencies in terms of rules and badges and gates and things that really bother me, personally. I've felt that we've somewhat lost touch with the community, and that's kind of hurt us locally.

I think our reputation has always been very strong nationally and internationally. We still are very strong internationally. Our reputation's probably the best, I mean, in terms of the few closest to CIL. You know, we're having a lot of difficulties and so the whole issue of advocacy versus services is a critical one. Finding the right balance, I believe, is really, really crucial. I mean, I sort of feel like it's become way too tipped toward just trying to fix the person's problems instead of teaching them how to fix the problems for themselves.

Johnson: Which is kind of like where we started when you mentioned that hospitals are all about trying to fix it. If they didn't fix it, it hadn't worked.

Chavez: Right, and it's kind of interesting because when our new director came on, we had a retreat and we made a circular graph talking about how an agency goes through a process. They become very bureaucratic until they sort of die and then have to be reborn and start over. I feel like we're post bureaucratic, near death. [laughs] You know, and so it's kind of scary times in that respect.

So the whole point is to get back to more of an advocacy role, and to where we're doing not just individual advocacy with the consumers that we're working with, but systems advocacy to make overall change and raise consciousness, which is what I felt like we did a lot more of in the seventies. I mean, the overall systems advocacy and consciousness-raising was what I thought we did a much better job at doing.

I think there's a lot of factors you can talk about in terms of just the social environment, political environment of this country, and the city of Berkeley, in general. I think things have really changed. I think it was a much more open environment for that type of change in the early seventies, mid-seventies--late seventies--for making that kind of systemic change, whereas

now it seems like it's gotten to be a lot more difficult. Or at least in the eighties, the late eighties, it seemed to get a lot more difficult.

San Francisco 504 Sit-in

Johnson: In the seventies you were looking at some ground-breaking legislation being passed, both on a statewide basis, and a national level: the 1973 Vocational Rehabilitation Act with section 504, which then led to the '77 demonstrations to get it actually implemented. Section 504 basically said discrimination in federal employment, federal contracts is illegal, as opposed to now when it seems, at some level, all the work's been done, or maybe that's the way it's perceived. That's what I get a sense of your talking of. Could you talk a little bit about 504 and specifically San Francisco in 1977?

Chavez: Well, I think what you just mentioned was really an important fact, which is that it wasn't written in 1977, it was written in 1973. I mean, it just took that long. Then the actual sit-in in the federal building to get it signed by Secretary Joseph Califano--this was something legally we had the right to long before the '77 demonstration. A lot of the people that were working behind the political scenes in the disability community knew this, and it just came to a head in '77 at the federal building in San Francisco when a bunch of people--a bunch of friends of mine--[laughs] you know, just decided they weren't going to leave that building.

I'm trying to remember if I was there that day. I think I was sick that day or my attendant didn't show up or something. I don't remember exactly what happened, but one of the women I was seeing socially was inside of the building and so it was kind of interesting because I was there demonstrating with everybody else, but I was like kind of locked out because once the sit-in started, then they wouldn't let anyone in or out except for like medical reasons. They were letting some attendants in and out, and some food and things like that, but otherwise it was a locked situation. The doors were locked and there were guards and it was a very interesting situation because people, you know, wanted to be in there. It became a situation where a lot of us who were demonstrating on the outside of the building wanted to join our compadres when they were on the inside and weren't even allowed to.

They didn't want any more disabled people occupying the building, so I remember it just being a regular thing to try to get over to San Francisco. We set up a van pooling kind of situation, and some people would go over on BART, but most of us went over in vans. We had all kinds of signs and buttons and chants and megaphones, and talking to people through the glass door, that's what I remember that really hit me.

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Chavez: Yes, I was just referring to the 504 demonstration and sort of being on the outside and what that was like. I just remember in some ways we were really into what we were doing, but also I remember it being a very much fun, social kind of thing, too. It was like the people were very jazzed about getting our point across, but we were also having a good time while we did it. I just remember that sort of whole social aspect of the political part of it.

I can remember it probably sparked my memory because I saw a film about the disability rights movement. There was a shot and I remember seeing myself in there. I had a lap tray on my wheelchair and at the time it was this very sturdy wood one and I would always give people rides on it. I mean full-grown adults. But I remember having this child, a friend's kid, on my lap tray and I was going around in a circle with a big sign sticking out of my backpack, and the little girl who was sitting on my lap was holding a sign. And she's just chanting away. You know, sign 504.

My only other real memories of that in terms of the participation was that I was part of the phone tree in terms of trying to get vans together. I also would help with some of the organizing around getting signs done--just the materials to make signs together for that. That's really about it until the actual culmination when it was signed and everybody came out and had a big rally and people talked.

I probably knew just about every person that was in the actual building. Most of them were good friends, so there was very much of a festive party atmosphere afterwards. I also remember them being exhausted.

Johnson: Did you feel left out because you hadn't been inside at all? Did you take on another role being one of the people on the outside, having a slightly different role to take in the demonstration?

Chavez: A little bit of both. I definitely felt like, Dang, I wish I would have been able to get in, but there was also a part of me

that was realizing my own limitations around my disability and thinking, Well geez, I probably would have ended up with a pressure sore or something if I would have been trying to sleep in those kind of situations. You know, people were literally sleeping on the steps and whatnot inside the building. For me that would have been really difficult with my disability in terms of the problems that I had--specifically related to like pressure sores--but other things, too, I mean, in terms of needing catheter changes and things like that. I'm not quite sure how I would have dealt with it.

Thinking back, I think that might have been part of my decision of why I didn't go into the building, because I can't remember if it was because of that or if it was because I didn't make it there on the day when they actually went into the building. My memory is just not that clear on that part of it.

Johnson: Was this a planned demonstration, or impromptu? Do you remember how?

Chavez: It was planned to a certain degree [laughs] but a lot of our, "planned" demonstrations were somewhat impromptu. I mean they were planned like someone said, "Well, you know, I think we should do this," and another person would say, "Yeah, I think we should do this, too," and that was about as much planning as there was. Then maybe there would be a meeting around it. Sometimes there wouldn't be even that much. It'd be like two or three people making the decision that, "Maybe we should go to Sacramento," or maybe, "We should do this," and then it was just, it would catch fire. I mean it was like one person would call another person and so on. They would call two people and the two people would call four people. It was like that. I mean, before you know it, the word got out really fast.

The grapevine in this community used to be so tight that getting the word out was not a problem; never an issue like it is now. I mean, to get a demonstration together now really takes a lot of work and a lot of planning and a lot of meetings and a lot of outreach and a lot of work. I'm not saying that it wasn't work back then, but it sure was a lot easier to get people together.

I think it was just, for one thing, people's motivation was so much higher back then because it really was a survival issue. I think for a lot of disabled people now--because of the fights we fought way back when--a lot of things are pretty much carved in stone, law-wise, these days and so a lot of people don't have to worry about certain things. They don't have to, you know. They can kind of go, "Well, I could go up to Sacramento and

demonstrate about this, but you know, if I don't, it's not like I'm really going to lose my IHSS [In-House Support Services] or anything."

Well, that's not the way it was for us. I mean, it was like you go to Sacramento or you might end up in a nursing home. That's the way we saw it. I mean, that black and white. I don't think people see it that way now. I feel like we're--I think there really was, you know, like a whole generation that--I don't want to say you had to like hand it to them on a platter, but that they definitely didn't have to fight for their rights the way we did.

Actually, it was interesting, because I was having a meeting with our director and we were talking about the different aspects related to this and he was wondering and trying to get a handle on why things are the way they are now as compared to the way they used to be. We talked a lot about that. I felt like there needed to be a lot of reeducation going on for generations that didn't have to fight for the rights that we had to fight for. So I felt like there was a real gap, especially in the eighties for people. If you needed an electric wheelchair you just asked your social worker to get you an electric wheelchair and they did. It wasn't this huge battle, you know, to get your needs met.

Johnson: You mentioned a number of battles--Transbay Terminal, San Francisco sit-in in '78.

Chavez: Yes, I mean, I wasn't an active participant in that particular one, but a lot of people I knew were. I knew Michael Pachovas, who was a friend and roommate, was very involved in that, and a lot of people I knew were involved in that. I think I went to one demonstration related to that and I'm not sure if I was laid up with a pressure sore at the time, but I think that might have been the case.

Lobbying in Sacramento, Utilizing the Media

Johnson: Are you talking about the battle, specifically in San Francisco, that you have mentioned with regard to IHSS?

Chavez: IHSS was a key. It seemed like every year was a battle. Yes, it was like every year they'd either cut it out completely, or cut it, or not give us our cost-of-living increase, so it seemed like every year that was a battle. Really, in the late seventies, I don't remember a year when we didn't go to Sacramento, and

usually it was numerous times. It wasn't always just IHSS. Often it was the bare bones. One time they were completely trying to cut out SSI, Supplemental Security Income. Another time it was SSI and SSDI, Social Security Disability Insurance. I mean, it seemed like a never-ending caravan up to Sacramento.

There was always a core group of us that would just get on the phone and call everybody we knew that had vans with lifts on them. It was also amazing to me the number of wheelchairs that we used to get into a single van. I mean, a regular standard sized Ford van, we would pack six wheelchairs into it. There'd be like two or three ambulatory people squeezed in between the wheelchairs. We would be like a big sardine can on the road up to Sacramento, you know? [laughs]

We made a lot of fun out of it, too. It wasn't just, you know, this sweaty work thing. But I can remember days when it was a lot of work, too, just in terms of dealing with the elements. Because it was so hot up there a lot of times, that you know, they were passing out. A lot of quads--a lot of people with disabilities--have problems with heat, so we would be like having water fights [laughs] and whatnot, just to stay cool.

It was always kind of an interesting thing in terms of, you know, which van you'd go up in because there would be the vans that were like full of marijuana smoke, you know, and then there would be the other vans. We always tended to make it fun enough to attract a lot of different people, you know. People would bring a portable ice chest with beer, and so we would turn our demonstrations into somewhat of a party environment, as well. But when it got right down to it, we were really a strong force to be reckoned with.

The other thing that we were very good at was utilizing the media. We made sure that the media knew we would be there.

I don't know if this country has just gotten so used to sensational things happening, violent things happening, but it doesn't seem like it's much news anymore if a few disabled people get together. It has to be a lot of disabled people and it has to be a real critical issue that can really touch people. But back then, I think it was novel enough that the media was always interested. We could always get them interested and we had a lot of allies in the media. Like I said, we utilized them well.

We knew that there was a lot of power behind a TV camera, so that was a big part of it. We would parade up to Sacramento and raise a lot of hell, and then do our individual actual lobbying where we would go around to different assemblymen and

assemblywomen and senators and talk to them individually about what our plight was, whatever it was, IHSS or SSI.

Then I can always remember how we would try to get home in time to see the news. [laughs] You know, rush back. This was like when VCRs were just starting, kind of thing, too, so it wasn't like you'd just preset your VCR before you set off to Sacramento so you could watch yourself on tape later. [laughs] There was this funny kind of thing to like try to get back in time to catch the six o'clock news. That was funny, so sometimes we would make a big deal of doing that and other times we would stay in touch with whoever we knew who wasn't going to Sacramento. So we would call them and say, "Okay, did Channel 4 pick this up, or did Channel 5 pick this up?" so we knew if they didn't that we would get hold of them next time to make sure that they did. [laughs] So like I said, we were really good at utilizing the media.

That's something we've kind of lost touch with is that, you know, you really need to know how to have the media as your ally. That was a crucial part of almost all our demonstrations in Sacramento.

Johnson: How did all this going to Sacramento help you? Did it help you pass laws?

Chavez: Yes, I think it did in some ways. But when you said that I can't help but flash on this one time when I was going to Sacramento and Ed was up there and we were demonstrating. I honestly don't remember what it was about--whether it was SSI cuts or IHSS cuts --but Ed was up there and he was passing out buttons about something. I had just assumed it was related to what we were doing, right? Whether it was IHSS or SSI or whatever, it was disability. No, Ed was passing out buttons trying to get a helmet law passed for motorcycles. [laughs] Why that came to me--but it did.

To be quite honest I was like not for helmets. I was like, Oh, so I'm wearing this button. Then I realized what it was and I went, "Wait a minute, what are you doing, Ed?" I said, "You're manipulating this situation!" Basically he was trying to turn this disability rally into a pro-helmet law rally, which was really interesting because that particular time we got totally upstaged because about 300-400 Hell's Angels, mostly, and other motorcycle gangs showed up in Sacramento and there are only about thirty of us. [laughs] We looked at the news that night and there was almost no coverage on the disability issues because there were 300-400 motorcyclists, you know, roaring up in mass. And they were protesting the helmet law.

But just for some reason, that funny story comes to mind. But I actually I need to use my recliner a couple of times, if you could pause that. [tape interruption]

No, there's just one more thing I want to add on Ed Roberts being the head of the Department of Rehabilitation. I think it gave us a lot of inroads that we didn't have before.

Disabled Students' Union

Johnson: You've mentioned a number of occasions the differences you see between the community of the seventies and the community today. When I spoke to someone on campus about the Disabled Students' Union, they said as of this year there is no Disabled Students' Union registered on campus.

Chavez: Ooooh.

Johnson: I'm wondering whether you see that as being indicative as this change?

Chavez: Yes, I think it is. It's sad to me that the political conscience isn't what it used to be. In a way it's good because I feel like the disabled population on campus has probably become such an integral part of UC Berkeley that they're not seen as a faction.

The fact that there is no Disabled Students' Union anymore bothers me, you know, in terms of I felt like there has been a lot of what would you call it--disability political apathy. I don't have all the answers to why that is. There's a lot of different socio-economic reasons. Things I already talked about before in terms of things kind of being handed to people and they didn't really have to fight for them.

I mean just to get into UC Berkeley, it's so hard for me to get used to calling it the Disabled Students' Program. It was really interesting yesterday at the veterans hall to hear Sue O'Hara constantly calling it the Physically Disabled Students' Program or PDSP, because that's what we called it. It was called Pedips. I mean, that's what it was; it was Pedips.

But no Disabled Students' Union, I don't know. I really wonder where the mind-frame is at in terms of the disabled students on the UC Berkeley campus and in the dormitory programs. I wonder if there is even a sense of community like we had. I think that was the one of the strong suits that we had. It's

always a double-edged sword. I mean, I think because we were somewhat segregated, I think we were stronger in some ways because we were more unified. Now, using the disabled students at Berkeley as an example, I think, like I said, they're probably so integrated, so homogenized that there probably isn't that strong sense of a community bond that there used to be.

I mean, some of them probably utilize the Disabled Students' Program for various things and that's it, and maybe have a couple other disabled friends, and that may be it, whereas before--I mean, especially all the way back to the Cowell days, you knew every other disabled person. Usually they were friends, or maybe they were adversaries or whatever but you knew them and you knew them well. I just don't get that sense anymore that there's that sort of tight-knit community, which would make sense if there's no Disabled Students' Union anymore.

Future Needs

Johnson: It occurs to me and you've used the word, it was a matter of survival. When you think of Maslow's "Hierarchy of Needs", it's those basic survival issues that you have to take care of first before you can take care of anything else. Maybe there's no perception of any needs in terms of the basic level. My question then becomes, what do you perceive as the needs, the fights to be fought, for you and for the disabled community, and the whole community? What fights are there now?

Chavez: Well, for me it becomes more an issue of the classic example of if you don't learn from history, it's bound to repeat itself. All these battles that we've supposedly fought and won, a lot of them are coming back around and have to be refought. I mean, we're still not at a proper SSI cost-of-living level that we're supposed to be, but I feel like there are people around that are getting the money and whatever, don't know this, probably. I think there's a general kind of lack of education and it's sort of like, oh, well, it's good enough. You know, I mean, I have my power chair, I have this, I can get attendants, you know, like you said, all these survival needs are met. I think that becomes in some way enough.

For me, in the disability movement, it's never enough because there's always going to be something that's going on that needs fighting for. Yes, I feel like I live in a fairly high-consciousness area in Berkeley, yet there's a community garden going on around the corner and I had to go around and fight, in a

real polite way, but fight, to make sure that it was made accessible. This is like a constant battle. I mean, an ongoing one.

Because ADA [Americans with Disabilities Act] is passed, I mean, it doesn't mean that big business and corporate America and whatever is going to implement it. All you have to do is look down the road a piece at the Oakland Coliseum and realize that there's been a multimillion dollar renovation and they didn't bring it up to ADA code so they're being sued. It's like round and round in the ADA-mandated paratransit system right now. They're not meeting the ADA mandate, so that is probably the battle front right now in the disability community that I don't see the masses fighting. I only see handfuls of people fighting. Most of them are old guard.

You know, it's not the new kids on the block that are fighting. A few, a few, and it's encouraging when I do see a newer disabled person or a young person that's out there fighting these new battles. But I do see the main battle ground is implementing ADA on many, many levels: on housing levels, on education levels, on just architectural barrier uses. It's going to be a constant, ongoing battle for many, many years to come.

Just like, just because ADA is passed, that doesn't mean everybody's implementing it. There's a few people that are smart and actually realize that the cheapest, best way to deal with the ADA is just fit it into your plans. You know, it doesn't cost a lot more money, especially if you're doing something architectural. Usually if you start it right from the blueprint level with the architecture, the cost is, if anything at all, very minimal.

I mean, this coliseum example, all this renovation is a great example because we're probably going to end up winning this lawsuit and then they're going to have to go back and spend all these millions more to change what if they had done it right the first time, if they had just followed the law, wouldn't have been that much of an issue and would have saved them a lot of money in the long run and made it better for everybody. Because that's the irony: everybody I've ever talked to that has dealt with specifically architectural barrier type situations find that it's better for the overall populace.

I mean, all you have to do is look at curb cuts and see, okay, well, who utilizes curb cuts? People on bicycles, people on skateboards, mothers with babies in baby carriages, little old ladies and their shopping carts. I mean, everybody utilizes curb cuts. It's just something that makes sense. Most of the things

that we're talking about on everything from an educational level to a housing level to architectural barriers levels, you know, related to ADA, is going to benefit everyone. People don't see it that way. You know, they think, "Oh, god, this is going to be so costly because I'm going to have to put in a ramp here," and da-de-da-de-da. And it's like, it's not. I mean, especially for new buildings, especially for new facilities, especially when they're already making changes.

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University of California
Berkeley, California

Disability Rights and Independent Living Movement Oral History Series

BUILDERS AND SUSTAINERS OF THE INDEPENDENT LIVING MOVEMENT IN BERKELEY
VOLUME IV

Frederick C. Collignon

UC PROFESSOR OF CITY AND REGIONAL PLANNING:
POLICY RESEARCH AND FUNDING ADVOCACY

An Interview Conducted by
Mary Lou Breslin
in 1997

TABLE OF CONTENTS--Fred Collignon

INTERVIEW HISTORY	70
BIOGRAPHICAL INFORMATION	71
I	
EARLY YEARS: RELATIONSHIP WITH ED NEWMAN, VOCATIONAL REHABILITATION ACT OF 1973	72
Family Background, Early Jobs	72
Ed Newman and Rehabilitation Services Administration	74
Acting Assistant Professor at UC Berkeley	77
Social Policy Studio and Involvement of Students with Disabilities	77
Launching the Center for Independent Living	84
Role of California State Department of Rehabilitation	92
Title VII of the Vocational Rehabilitation Act of 1973	96
Nixon Veto: Newman Fired, 1973	98
Title V Civil Rights Provisions	102
Minority and Gender Issues	103
II	
MOVING FROM A CHARITY MODEL TO A SOCIOPOLITICAL MODEL	107
Charles Cole Dissertation and Social Technology	107
Disability Lobbies	114
Judy Heumann and the Voucher System	116
Berkeley Planning Associates Formed, 1972	120
Research Studies: Independent Living Policy Issues, Education, Employment, and Race	123
Transition from Charity Model to Sociopolitical Model	128
Ed Roberts' Impact on the Independent Living Movement	129
Evaluating the Effectiveness of Title VII Programs on Independent Living	131
Health Insurance Studies: Supporting the Americans with Disabilities Act	138
Issues of "Habilitation" and "Rehabilitation"	146
Disability Studies Program at Cal	148
Future of Disability Programs and Politics	153

INTERVIEW HISTORY--Frederick C. Collignon

As a member of the faculty of the Department of City and Regional Planning at the University of California, Berkeley, for three decades beginning in 1970, Professor Fred Collignon contributed to the evolution of the disability movement in Berkeley and nationwide in numerous respects. Most notably he conducted or supervised extensive disability and rehabilitation research that helped support independent living principles and legislation, employment opportunities for people with disabilities and organizational funding. He mentored students with disabilities, offering the first independent study courses in disability policy and serving as faculty advisor to students on disability issues. Calling on his extensive contacts with various federal government agencies and departments, he helped secure funding for the Berkeley Center for Independent Living where he served as a member of the board for ten years.

In 1972 he founded Berkeley Planning Associates (BPA), a national planning and public policy firm where he supervised research on such topics as the cost of reasonable accommodation in the workplace, the effectiveness of the vocational rehabilitation system and access to health insurance for people with disabilities. He served as president and CEO of BPA until 1994. The firm's research on the cost of reasonable accommodation was used by advocates for the 1990 Americans with Disabilities Act to show that accommodating people with disabilities in the workplace was affordable for employers.

In the late 1990s he began co-chairing a project sponsored by the UC Chancellor's office to establish an interdisciplinary disability studies program at UC Berkeley. Before joining the faculty of UC Berkeley, Professor Collignon completed his undergraduate work at Columbia University, and received his M.A. and Ph.D. from Harvard University. He grew up in Baltimore, Maryland, and worked with his family's small business there as a teenager.

Professor Collignon was interviewed in three sessions beginning in August, 1997, and concluding in April, 1998. Interviews took place in his office on the UC Berkeley campus. Professor Collignon spoke eloquently and at length. He was able to recall relatively easily key events in the history of the disability movement in Berkeley in which he participated. The interviews were transcribed by the Regional Oral History Office, lightly edited by project editor Sharon Bonney, and returned to Professor Collignon for review. He lightly edited the transcript.

Mary Lou Breslin, Interviewer

May 2000
Regional Oral History Office
The Bancroft Library
University of California, Berkeley

BIOGRAPHICAL INFORMATION

(Please write clearly. Use black ink.)

Your full name Frederick Conrad Collignon Jr.

Date of birth Dec 17, 1943 Birthplace Baltimore, MD.

Father's full name Frederick Conrad Collignon

Occupation Mgr. Small F&E Retail Business - Inner City Birthplace Baltimore, MD.

Mother's full name Margaret Ann Roeder

Occupation Homemaker Birthplace Baltimore, MD

Your spouse Joan Frier Hauseuman

Occupation Legislative Aide, City Council member Birthplace Cleveland, Ohio

Your children Katherine (born 1973), Genevieve (born 1976)
and Robert (born 1981)

Where did you grow up? Baltimore ~~County~~ County, MD.

Present community Berkeley, CA.

Education B.A. summa cum laude - Columbia College (NYC),
M.A., Ph.D. Political Economy & Government - Harvard Univ.

* Occupation(s) University Professor, Public Policy Analyst, Program
Planner, and City Planner

Areas of expertise Program Planning and Management, Public
Finance, Community Development, Regional Planning, Social Policy,
Program Evaluation, Labor Market Programs, Disability

Other interests or activities Berkeley City Councilman - 2 terms;
setting up Disability Studies program at U.C. Berkeley; baseball,
science fiction, Stamp collecting, hiking

Organizations in which you are active Calif. Food Policy Advocates,
Berkeley Boosters/PAL youth programs, Newman Catholic Center,
Claremont-Elmwood Neighborhood Assoc.

SIGNATURE Frederick Collignon DATE: 5/19/00

If this meant Part Jobs/Employment, see reverse

Occupations as Jobs.

Associate Professor, Dept of City & Regional Planning,
 University of California, Berkeley 1970-date.
 Dept Chair - 7 yrs
 President, Berkeley Planning Associates (research
 organization with disabilities among its & ma
 specializations 1972-1996
 Program Analyst, Bureau of the Budget, Executive
 Office of the President, Washington DC.
 1966-67
 Legislative Analyst, U.S. Representative Clarence Long,
 (MD.), U.S. House of Representatives 1963, 1965
 Economist ~~and~~ and Policy Analyst, Abt Associates
 (research think-tank), Cambridge, Mass. 1968-

INTERVIEW WITH FRED COLLIGNON

I EARLY YEARS: RELATIONSHIP WITH ED NEWMAN, VOCATIONAL
REHABILITATION ACT OF 1973

[Interview 1: January 29, 1997] ##¹

Family Background, Early Jobs

Breslin: We're just beginning our first interview, and I'd like to hear a little bit about your family, your background.

Collignon: I was born in Baltimore, Maryland, of parents who never had moved out of the state. The family had immigrated there--I was third-generation--German immigrants in the 1880s--one side a farmer, the other side an artist. As I said, my parents always lived in Baltimore. I grew up in Baltimore, I went to college at Columbia in New York City, and I then went on to graduate school at Harvard--but during the entire time period I was also working because I had to work my way through school. So the good jobs were the ones in Washington, D.C., where I worked as an aide to a congressman for two years and then subsequently with the Bureau of the Budget and the President's Office, now called the Office of Management and Budget [OMB], where I had responsibility for the District of Columbia, transportation, and a few other stops in between. Once I would work there they would authorize me to do more activity while I was a student, so it became nice money. The bad jobs in between were selling souvenirs at football games and working as a cook and doing construction and working in a coal and fuel oil firm and a few other things that we don't put on the résumé anymore [laughs].

I finished my degree at Columbia in '65--braggadocio: with summa--and I did my doctorate at Harvard, which--actually, before I finished my doctorate I came to Berkeley to teach and

¹## This symbol indicates that a tape or tape segment has begun or ended. A guide to the tapes follows the transcript.

subsequently followed the doctorate in '72 or '73--somewhere in that time period.

The key part relevant to disability, though, were some of the jobs I had. Toward the end of my doctorate, after I had finished orals, I took on a job with what was then a growing firm called Abt Associates--for Clark Abt Associates. At the time I joined, I think I was the sixtieth employee; this becomes pertinent because Abt used to brag that it was the largest social science applied research firm in the country, and it got as big as 1600 employees. I was number sixty in this group.

It was a fabulous job. Social science applied research consulting was just beginning to boom. I created for Abt an entrée into the economists at Harvard, and they once had a faculty meeting at Harvard--highly concerned because their best doctoral students were not serving as their RAs [research assistants]; they were working for Abt at five times the wages--it wasn't a lot of wages, but it was five times the wages they were paying--and I was the conduit for a lot of these people. The fun part of working for Abt was they were sending you all over the country. At a very young age you were able to bluff your way into marvelous kinds of things on policy work, and I enjoyed the travel. I enjoyed the policy work. I found the work absolutely fascinating. It was exactly opposite that which usually in academe they're trying to have you do: immersed, directly working with politicians, policymakers, et cetera, in government, community organizers--now there are all kinds of these firms around; they've been around for two or three decades. But back then Abt was one of the very first of its kind.

Breslin: Who was heading up Abt at the time?

Collignon: Clark Abt was president throughout most of this history. But how this meshes into disability is the following: I spent a total of five years with Abt--all while still either doing a doctorate or then later while teaching, and I was a senior economist by the time I finished. Abt Associates won a very large job to evaluate what was then called the Neighborhood Services Program. The key to this is that it was the predecessor to model cities, but it was a demonstration program in seven or eight cities that was jointly sponsored by five or so large federal departments--Housing and Urban Development, Education, whatever was then Health and Human Services, and a few others. The whole point of it was to work with local community organizations to provide better services, better development programs inside inner-city ghettos to show that the

government could coordinate its efforts. I was in charge of the evaluation for at least two of the cities and a couple of the issues that were across the entire demonstration.

Ed Newman and Rehabilitation Services Administration

Collignon: That was interesting in its own right, but the key to this was that the federal monitor for this from the President's Bureau of the Budget was a fellow named Ed Newman. Ed Newman, prior to this job, had been in Massachusetts as Elliot Richardson's head of the mental retardation division--I think they were still using that word in those days--and had gone on to the Office of Management and Budget. During this three- or four-year evaluation study, Ed and I became close friends. One of the things I was doing for the national demonstration was a study of how the federal agencies coordinated their efforts. That meant I was talking to all the various feds, and Ed Newman had to be my broker as we set up those interviews.

To show you the implication, when the study was done I ended up giving personal briefings to all of the undersecretaries for the five departments--that's pretty heady stuff--on how to coordinate government services. One of my conclusions was, by the way, that often the feds can't begin to figure out how to coordinate; it's the local service organizations who make the coordination happen by putting the services together on the local scene. Most of the federal efforts usually ended up failing. But I suggested a lot of things they could do, et cetera.

So I'm working hand in glove with Ed Newman. We built a close friendship; we would often go out drinking, I would spend nights at his house afterwards, and we spent in a six-month period a great deal of time talking because we had two issues we were trying to resolve: Ed was campaigning for the job of Commissioner of Rehabilitation Services, and I was trying to decide whether to get married [laughter]. So we would basically sit and drink, and since I was a very political person--I had worked for a congressman, and I had been in politics literally growing up and so on--I would strategize with him on the politics, and he would advise me, "There's a time when it's sensible to shift your gears and get married, and family's a great thing," et cetera. The positive side to all this is that Ed got his job as commissioner, and I did marry the lady to whom I'm still married twenty-seven years

later. So it was very positive on both sides. It was a very close friendship.

When Ed got his job of Commissioner of Rehabilitation Services [Administration], he then hired Abt to basically be his personal consultants in setting up shop. That included a study effort that led to a reorganization of Rehabilitation Services Administration [RSA]. This is all still before getting to Berkeley. Another fellow named Marty Gordon and I were responsible to keep people's responses for that study. But what happens in Washington is that new heads of agencies, at least in those days, were able to bring in one or two people to be their personal special assistants whose loyalty was to them. And in those days you could also instead bring in consultants. We were the consultant that Ed brought in. Literally, I interviewed at some point virtually everybody in RSA and advised Ed on who was good and who might not be as good. We did a reorganization study that led to a massive reorganizing of all of RSA that most of the staff bought onto because of the way we staged it--I don't know if that's relevant to your concerns; I could talk about that.

We also, at the very beginning of this, went out and talked to the most powerful figures in CSAVR--the Council of State Associations of Vocational and Rehabilitation Administrators--to get their perspective on what was effective and what was less effective about how RSA was conducting its activities. So we had a state perspective. Now we talked to the disability lobbyists that were in Washington, but these were early days: you had a blindness lobby, and you had a deafness lobby, each of which had one of their own in RSA as the head of activities affecting services to those groups. The other lobbies were basically--there was a paraplegic association, basically controlled by war veterans--and I'm not sure if there were any others that I can remember at this stage that were major political players. But you had nothing that resembles the disability movement now.

As someone who had always worked at the neighborhood level in inner cities, I can say, "Wait a minute. What about an organization that instead of being totally organized around running blindness vending stands--which was a major source of money and had business interests--represented the person on the street who happened to experience a disability?" It was very evident to me, and it was evident to Ed, that that grouping did not exist in the disability politics.

Breslin: Let me just interrupt you one second and ask you to clarify the dates. This is pre-1970?

Collignon: This is 1968. That's when my relationship started with Newman. And the studies here--Ed took over as RSA commissioner--you can check this one out more formally, but my guess is that it would have been around the end of 1969 or 1970. In this early '68 and '69 period he is in the Bureau of the Budget running this study and thinking about how to be made RSA commissioner. This study within RSA probably begins after [President Richard M.] Nixon's 1968 election. Newman probably gets his appointment in mid-'69, and there's this sort of crash study and I'm working on this fulltime.

Breslin: And you're in the midst of your doctorate as well.

Collignon: That's right. I'm still supposed to be writing my doctorate.

Breslin: You're a student but you're really doing this.

Collignon: All the time I was at Columbia I worked a minimum of halftime or more to finance my way through, and except for the very first year of my doctoral program--when I gratefully had a Woodrow Wilson Fellowship--I worked fulltime throughout the rest of my doctoral program because that was how I was going to get the money to finance it at that time.

Anyway, so we are doing these studies, and among the other things Ed was very clear about wanting to do was trying to use the next time that the--back then it was called the Vocation and Rehabilitation Act--came up, to try and do it as a major time to reconsider the program as a whole. We started developing a strategy group to try and think of what might happen in that and how to make that social change happen. Now the key player again is--Ed Newman was a former professor, I believe, at Tufts [University] before he took over the state agency in Massachusetts. But he was a social planner by background, and very much thought about social change. That was very much part of my thinking at the time as well.

One of the things that basically everyone always said is, you know, if political reform happens, there always has to be a thousand authors. However Abt does it, if it looks like you did it, you will probably be beaten. So the question was, How do we persuade the retiring long-time lobbyist for CSAVR--whose name was E. B. Whitman, if I remember, and there was another nickname he had that I've forgotten. Whitman, since he was going to retire, we thought, Let's persuade Whitman that this is his moment to transform the VR Act into what he thought it should be. The issue was also to get several of the congressional committees into transforming the act. So a lot of parties would say, "Hey, this is my opportunity to transform

the act." Ed Newman was a great believer in creating lots of credit around this. This is related to Berkeley--finally the story evolves.

At a point in doing all this, I chose to leave Abt and accept an acting assistant professor at Berkeley. Ed was frustrated because Ed had offered me a job.

[tape interruption]

Collignon: Remind me where we were.

Acting Assistant Professor at UC Berkeley

Breslin: You had just come to Berkeley.

Collignon: Okay. Ed had offered me Director of Policy for RSA, which was, for a young kid of twenty-six--just getting married--a hefty thing and big money for those days, GS-15, and I was thinking, "I haven't got a doctorate; how could I qualify for this?" He said, "Don't worry; most people don't have it." But I knew there was something else; I thought I would never get political clearance for it because I had been an antiwar activist, I was listed with HUAC [House Un-American Activities Committee], and this was the Nixon administration.

Breslin: Your FBI file was as long as the rest of us.

Collignon: It would never have worked was my judgment at the time. Now I know enough actually that for GS-15 they might not even do a political clearance because it's civil service. But I didn't know enough about the bureaucracy at the time to realize it may have worked. So I'm here, but I'm promising Ed that we're going to continue to work closely.

Social Policy Studio and Involvement of Students with Disabilities

Collignon: Once here, Ed literally demanded and got from his research shop--which in those days was located not in NIDRR [National Institute on Disability and Rehabilitation Research] but inside what was then called RSA. Some small amount of money--I think it may have been \$10,000, which looks trivial now but in those

days was not that bad--to do policy research here at Berkeley. That was the first year, and then it became a larger research grant with more significant dollars, and it was the only policy research center that Voc-Rehab was sponsoring in those days.

Breslin: And is this the Institute of Rehab Services?

Collignon: No. Both of these grants flowed through the Institute of Urban and Regional Development here on campus, and which is still on campus. So the first is a \$10,000 grant--the next grant was like a three-year grant. I think it was around--boy, getting bad on my memory--\$60,000, which was a lot of money in those days in what it could buy. But literally it was the only policy shop in the country, and that was so that I could keep advising and doing work for him. And this is going to become important to the Berkeley model.

While still consulting with them and being part of what then we called the Newman Mafia in Washington, which was the people working on trying to think through the strategy of getting a brand-new '73 Rehab Act. On campus, in this department [City and Regional Planning], we had what was then a social policy emphasis within the Ph.D. program that had been funded by the National Institute of Mental Health. I was brought in as a regional development specialist and very quickly said, "Oh, but will you also work with social policy?" because my doctorate was in political economy and government. It was economics but also poli sci, and I had this political activist streak and had worked on all these things.

I was allowed to set up a studio for the first time on social policy issues. A studio in this department is where you have a group of students working together on an issue, usually for an outside client. In this case the initial outside client was RSA. In the first studio we focused on disability policy. Well, no one had ever focused--we didn't have a CIL [Center for Independent Living] at that point. The Disabled Students' Project was just getting off the ground, and--

Breslin: Point to the specific dates here if you can.

Collignon: The first studio was probably spring of '71, and in that first studio there were only four or six students. The next year, we had the larger grant and the studio went up to something like fifteen to twenty. I can't recall whether it was the first year or the second year that we started getting a more significant number of students with disability. Again, there were not a lot around campus. But we had in the year I'm thinking--it was either the first or second year--Larry

Biscamp, who became the first founder of CIL, Herb Willsmore, Judy Taylor, Bob Metts--who later did his doctorate in economics, and had a disability--Dave Konkell, who was blind, and a few other folks.

Breslin: These were either in the first or the second of the studios.

Collignon: First or the second of the summers. And I did the studio every year for a bunch of years.

Breslin: How many? Do you remember roughly?

Collignon: Focusing uniquely on disability, probably around three or four. And then in the seventies I did a course on disability policy. That had Judy Heumann and a few others that were in it. There was the one-year grant, and then there was the three-year research center on policy. Then they gave us a training grant where we could recruit people with disability nationally, specifically on this issue of policy. That we had for two or three years, and then we asked them to stop it. What happened in those days was that they would tell you the training grant money you had as of October--one month into the year you're supposed to be financing. Here we were trying to recruit people with disabilities from across the country around policy, and I couldn't bring somebody to Berkeley not knowing that I had the money in my back pocket. But I wouldn't know I had the money until they were here already. I said you can't operate a training program that way.

Breslin: Okay. Stop a second, and let's take us back to two issues here: the studios that you offered--and that eventually were attended by people with disabilities--consisted of what types of issues, when you say "disability policy"?

Collignon: The first studio literally had as its theme--let's assume that they revise the Rehab Act; what do we want to do with it? That probably was still the theme of the second studio. That was the studio as a whole, and students could do individual papers within it. For example, the students with disability--Biscamp, Willsmore, and Taylor--worked for a very key player in this period, Chuck Cole. Chuck was not disabled or he had some health problems; I would not have called Chuck as having a disability. They did a study of the training programs for rehab counselors around the country. They literally sent out letters, got the brochures for all the training programs, looked at their courses, had ways of categorizing programs as to what they taught and what they emphasized. They sent out questionnaires, many of which got answered, and they wrote a working paper that we issued through the Institute of Urban and

Regional Development. It was an evaluation of those from the perspective of people with disabilities. Now forgive me because back then the phrase "people with disabilities" wasn't used; it was probably called "of disabled people."

But what happened with that study--basically what they showed was that the training programs had very little focus on the kinds of living needs that were experienced by a person with a disability. They were very heavily focused on psychology, if you will. Their phrase would have been shrinking the heads to a certain mindset as if the problem was the psychology of the person with the disability rather than having truly functional needs about finding housing, getting transportation and access, figuring out how to get to work, getting the wheelchair repaired, et cetera.

If I remember in that report, they also recommended what they thought should be a desirable training program for VR counselors. Well, there was no such study anywhere in the world at that point doing that. I'm pretty sure now that that came out of the first seminar, and the reason is the total price of the first seminar was \$10,000, so that was merely one of the stuff that got produced for \$10,000.

Later, Ed Newman was before a Congressional committee and was asked to talk about the kinds of research being sponsored by RSA. Among the two or three he brings up is that study. And he's asked, "How much did that study cost you?" And he said, "I think we got that one done for only \$50,000 or so." Congress was pleased with a study of that magnitude that came out for \$50,000 [laughs]. The reality is that it was one of the studies completed for under \$10,000. The fact that both Congress and Newman could so misjudge and think this study clearly must have cost this much to do, and the worth was seen as far greater, shows the significance of what was happening. And was also introducing for the first time, from my perspective, a perspective of disabled people into thinking about the design of rehabilitation programs, which I thought was very important.

Now the difference is--there's always been the perspective that VR routinely would train people with disability to be VR counselors and to become policy makers. And those people would say, "Well, there's the perspective; here they are within RSA, they're VR counselors, what have you." But they had all gone through the trainings which taught them a rehab philosophy as defined historically by those who were thinking rehabilitation. It was not coming, if you will, from an unprofessionalized person with disability, and that was

the really dramatic significance. None of the students with disability were even thinking, at that point at least, about becoming rehab counselors. They weren't sure what their career lives were going to be, but it certainly wasn't going to be serving as a rehab counselor as they saw them. So it really was a very different kind of perspective.

Breslin: I want to hear about your experiences with your training program nationally, but I want you to think back a little bit about your early relationships with the group of students who participated in your first two studios and tell me a little bit about your recollection of them and their role on campus and your role with respect to them.

Collignon: Okay, and I'll tie it into CIL because that's where this thing presumably in part wants to head. Number one, they were incredibly bright, and I would say brighter than the typical Berkeley undergraduate. These were all undergraduates even though they were attending a graduate studio. A number of them subsequently went on, and went into our master's program here and became graduate students. But at the time they were initially participating, they were from the special project on campus for disabled students. They were definitely brighter than the typical student. And I would argue, kind of like the arguments that have been made for minorities--or way back, women, et cetera--you had to be brighter than average in order to make it, and I think that certainly characterized the individuals that were there.

At that point there was no community outreach from campus. This is all pre-CIL. One of the challenges that we would make in class was--as we tried to think about how you transformed a rehab system--what do you do to get better services in the community? We've critiqued what's wrong with rehab counseling, that it doesn't focus on functional needs. They're in a planning program which, by its very nature, talks about housing and transportation, et cetera. So in some sense, the city planning program is a very logical place to be, given the focus on functional needs in the community to live, for people with disability. I recognize now that it was a very logical department--probably even more logical than a public policy school would have been--for that type of effort on their part.

They had their needs met on campus; the question was what happens when you moved off campus? As I perceived it, a major desire of disabled students on campus was to get out of Cowell, to have a place in the community, and have a more private life. The private life was there partly because they wanted a chance

to socialize, have sex--this is still the seventies period--to drink, try a little drugs. I mean, all this was part of what it meant to be a student in that early time period. But really, more generally, to control their own lives, and I think they had that kind of degree of freedom in their lives, that they were not going to be able to have living in the Cowell Hospital.

Some of these [students] were initially in Cowell and then had moved out to get an apartment. The problem is, where do you find an apartment that's accessible to a chair? Major problem in Berkeley at that point.

Now, I want to say this because it's fair to recognize: my department already had some association with disability even prior to my seminars. That's because there had been a seminar on service planning, where one or two of the graduate students had chosen to focus on disability access, and one of those was Ruth Grimes. They had done a survey with campus students who had disability of which streets should have priority for ramping and cutting the sidewalk in order to provide greater access to people with disability. That study probably had been conducted around '69 or '70. It was done in the name of general service planning; it wasn't done in the name of disability policy. The whole seminar or workshop hadn't focused on that; I think it was merely Ruth Grimes--and maybe another student jointly--had decided as their project to work with disabled students.

That report had been done, it had gone to City Hall, and it had become the basis for city policy as to which sidewalks they would work on first. In retrospect, it's clear that you really didn't have as broadly organized a community base of disabled people, so it was what streets were most important from the viewpoint of students with disability perhaps more than it was the general community out there.

Breslin: Do you have specific recollections about specific people during that very early period when you were first here on campus? For example, Ed Roberts and--

Collignon: Okay, the key with Ed is--Ed at this point was still a legendary figure, but Ed had moved down to I think it was Santa Cruz [Riverside], to run a disabled program down there. At the key point we were forming CIL, Ed was not in Berkeley; he was at another campus. Now I'm trying to remember what the year was with CIL--'72 or '73?

Breslin: I believe it's '72.

Collignon: Okay. Ed may have been here the first year or so, but then he had gone to Santa Cruz [Riverside]. Now when we were actually forming CIL, he wasn't in Berkeley.

Breslin: He was not on campus when you first came here in 1970?

Collignon: I can't remember whether he was on campus, but by the time we were working on CIL he was away.

Breslin: Did you have a relationship with him prior to that?

Collignon: I had a relationship with Ed, and I'm trying to remember where I first encountered Ed. I certainly knew Ed throughout this period, but boy, I can't remember where the first relationship was. I'm sure when I first met Ed I did not understand his larger prominence, but I came to know it. Let me go through the story; maybe it will bring some of this stuff back. The students in the class, as they talked with us, also began talking about the need to do something that was more community based. We had debates, and it's important to unite campus students with disability with people in the community who are not necessarily students. This was a big issue.

The argument was, How do you get the campus project for disabled to do that unity? And the concession was one needed something like--and I don't think we necessarily called it a Center for Independent Living, but something like that happening. Some of the students with disability began working on that, and some of our students without disability, who I could assign from our grant project, would also work with them. A woman named Barbara Thompson in that time period--later on Chuck Cole, and I think Sue Stoddard began working in the context of one of the grants on some of these issues in trying to think about how you create this kind of grouping.

It was a big debate within the campus program about whether they should do this. It was not an obvious "Oh, yes--welcome to the community." Part of the argument was there are limited resources, and if we spend the money on those folks who are not on campus it's going to have fewer resources to meet the needs on campus, and that was seriously thought of as a potential problem. It was perceived earlier, I think, but nowadays I'd call it the politics would change of the campus program the moment they were out there in the community as a whole. My perception was that as individuals became leaders on the campus program, they often might worry about whether they would still be the leaders if somehow there was a larger constituency choosing them. Off campus, they would often discover what is often true in Berkeley: wariness of the

Berkeley student, even if they had an obvious disability. It was like "Well, wait--you're a student, you're privileged, you're a special person, and you're going to come in and tell me what to do?" A major kind of dilemma.

Now in these early discussions, it's hard to remember when I first met Phil Draper and some other folks that were in that time period.

Launching the Center for Independent Living

Collignon: --because Ed was a--I don't know if he was yet a myth or a legendary figure--but he was obviously one of the people they most respected. That's from having been a leader in the early movement to create the campus project. But when they actually decided to launch the center, if I remember, the first official head of the center was Larry Biscamp, who had been one of the early students in the group. And Larry, I think, was the official disabled person who was the head of the CIL for maybe the first two or even three years. Larry has been lost to history because my understanding is that Larry's disability later worsened and he was put in a nursing home.

This has been told to me by several CIL leaders that's been very embarrassing to the group as a whole: the first leader of the independent living center lost to a nursing home. There was also some degree of scandal with regard to Larry's household situation, and I don't want to comment, but whatever happened there meant that he was seen as not necessarily the model type of person that they wanted to cite. But the irony is, in some ways, Larry is almost forgotten. I often hear Ed founded the center, and Ed was not the original head or founder. This other group did it--absolutely talking with Ed wherever he was and so on. But Ed was not the key mover and shaker--he created the campus project. CIL wouldn't have happened if he was not there.

I have a very still-vivid meeting that hangs out of my mind from this period because it was very emotional for me. I met with disabled students--I think it was in a building behind Top Dog. My memory of that meeting which stood in my mind--and my guess is that it's probably around '72 or something like that--is that it was a meeting about whether to really launch CIL and what would happen to individuals if the resources got diverted--and I'm using that as an economist's phrase. This money essentially means that it will not necessarily go to

students on campus. Potentially, it would be spread across the larger community. The phrase was, "We have to cope with so much in our lives and right now make it as a student. And this issue is, somehow we're supposed to be out there in the community." This was the big debate that was happening among the individuals with disability that were in that room, but I was being brought in there as an academic, as maybe an advisor to a few of them--sort of make this argument of, "Why should we be out there in the community?"

Breslin: Who attended the meeting? Do you remember?

Collignon: My image is that there were on the order of a dozen or more people in the room. I'm sure that Biscamp, Willsmore, and Taylor were in the room. I don't believe there were community people; I believe it was solely students. I'm pretty sure by the nature of the conversation it was students. I'm sorry I can't do more on the grouping.

But what I remember is that I had read enough rehab counseling books to know of the "poor me" counterstrategy that individuals with disability sometimes use to evoke sympathy when they want to be different. I thought I was hearing stuff where I was trying to have emotions manipulated. They have so much to go through and were asking literally go out in the community and do some stuff--we had a grant we were preparing at the time. I played hardball; I swallowed my actual emotion and argued why they as students owed it to the community: they had the leadership skills, they were unique, privileged, special people, and they had this need. And they wouldn't be that hurt; if they did it right they could get their own needs met while meeting other people's.

I went home, and I cried that night in front of my wife--something I don't like to do--because I had thought I had been a son of a bitch. I was play-acting; it was something I had learned while working for the congressman: whatever your emotions, you can often counter by acting belligerent and strong why you should do this but, but never show the emotion. I was absolutely torn apart, I remember, by what I was hearing, and when I went home I kind of let it all out--"Am I doing the right stuff?" I don't believe in any sense that I persuaded--they had to make their own decision. But I remember it as an incredibly emotional meeting.

Breslin: Tell me a little bit about the perception of resources by the group. It seems as though that was one of a number of issues--a key issue, apparently.

Collignon: They had some money from the university--and I don't know that there was any other major money that was part of what they were currently doing--and it supported their own services then as students. But the question was, if you were to start serving the broader community, it was going to go a lot less further.

Breslin: That small amount of university funding would--the perception was that that would be spread out to serve the community and that was at the heart of one of the concerns.

Collignon: That was certainly one of the big ones. And the other one was that people were trying to make their own lives--they were not necessarily sure they were going to stay permanently a part of the community--if I'm going to be here for four years as an undergrad, do I want to spread all that out when in fact, you know, I'm going to be going back home to wherever my parents were, et cetera, and my commitment to the Berkeley community was much more tangential. That's a perfectly reasonable stance; it's the way most students often think as far as getting involved in the community--most students don't get involved in the community because they don't identify with the community.

What was happening in Berkeley was we were getting ramped streets. There weren't many cities anywhere in the U.S. that were getting ramped streets for those kind of issues. We got from Ed Newman or the CIL--the CIL got an initial grant from Ed Newman, and my memory in part was--and I believe it was the first grant--that I got a call from Ed Newman. The issue was if I would guarantee the grant to him in the sense of, "Okay, I'm accountable." And I said I would, and I believe my name was on the first grant.

Breslin: I want you to back up if you would. Think about the conceptualization of that grant and who was involved. Tell me a little bit about the circumstances that led up to that grant.

Collignon: The grant came about because of the section--the grant did not arise out of the '73 Rehab Act. But because the '73 Rehab Act was being anticipated and people were working on it, the grant was seen as trying to give some reality to a concept that was there of a community-based organization run by the disabled for the disabled [chuckles] and, importantly, that it was run by the disabled. Newman was interested in providing some support because Berkeley looked like the one place that was close to having it. The rival model was called the Texas model in Washington at that time, and it was much more of a halfway house run for the disabled by non-disabled professionals.

The contrast was the Berkeley model, as it was called in Washington, because it was coming out of disabled people. But the issue was, how do you make it a more real type of thing? Early issues on, as I recall, were trying to create more available wheelchair repair--that was an issue from the very beginning, which again shows that individuals in wheelchairs were the dominant group of activists that were in that earliest round. And I can bring in some more examples as CIL evolved.

Trying to find and list accessible departments for people was, as I remember, the second major--. And the third was more simple: just an ability for people to get together to talk about how they were coping with what we now call independent living, where you could have peer counseling--I guess that's the word we would use now; I don't remember if that was the word that was used back then--but a place where people with disability could meet to talk about their coping strategies and how they were handling both the welfare systems available to people with disability but also more functional kinds of needs in the community. People with disability in the community who were not students could be part of this grouping, so it had to be off campus. It could be close to campus, but it had to be off campus--that was the key factor.

Breslin: This was '72?

Collignon: My memory is that these discussion would have been around '72 or maybe early '73. It was prior to the formal launching of CIL.

Breslin: I'm not sure, but I think it was incorporated in '72, but the funding would have flowed following the incorporation. But you were there; I wasn't.

Collignon: I don't think the original grant was a big grant; it was more on the order of \$10,000 or \$20,000.

Breslin: Tell me about the grant a little. Tell me about its ostensible purpose.

Collignon: Its purpose was to give them some money literally to get the CIL going, because Newman had a lot of interest.

Breslin: Rent, phones, basic general operating expenses, was what its purpose was?

Collignon: Right. And it was meant to be as strings-free as possible. The call from Newman was to make sure that--again, these were "unprofessional" people writing a grant--to make sure that they

were not going to misuse the money. That's why I got the call asking for the--what we did then within the larger research grant is, we assigned one of our staffers--at least 50 percent time; I can't remember if it was 100 percent time--to work with the students. I believe the original staff assigned was Barbara Thompson. Barbara was an African American woman who did her master's in planning here but had a lot of community planning experience. She was sort of available just to help them on different kinds of things. Over the years of the research grants there was always a part of one of the FTEs [full time equivalents] that we would assign to work with CIL.

From the beginning, the ground rules are that people with disability had the right; it's their program, they're going to run it, they can make their mistakes, but your job is to--if you can spot some of the mistakes--help them avoid them and be available for some of the technical background in how you do some of the stuff such as they may need it. Again, our interest came out of the fact that when we were doing this larger strategy for the '73 Rehab Act, one of the beliefs was that we needed to create a lobby that represented, now what I would call grassroots disabled, as opposed to the existing organizations that would be more community based, not necessarily controlled by professionals or required a person with disability be professionalized in order to be an activist in it. And we ideally wanted it to cut across disabilities because we believed that one of the fundamental problems that was happening to Washington politics was each of the disability groups played for their own unique interests.

I don't want to say be damned with the others, but pretty different--I mean, certainly the blindness and the deafness groups, as far as we could tell, were not that concerned with others. The paraplegic association of the veterans was very active and obviously provided a major political stance with people with wheelchairs. We actually did want it from the beginning to be a much broader group, but my memory of those early days was that the bulk of the people involved were wheelchair disabled.

Breslin: Do you have any memory of people with other types of disabilities in the student group?

Collignon: Well, now I use the case of Dave Konkell. But I don't remember Dave Konkell at the founding of CIL. My memory of Dave is a year or two later.

Dave was a blind student, brilliant, who was being mentored a bit, I think it was by Aaron Wildavsky, who was a

major political science figure nationally but also in the public policy school that was just being founded. But Wildavsky apparently had been mentored by a blind professor in poli sci when he came along as a student. And he took a special interest in Dave.

Dave got involved with CIL, but it created great friction within the blindness organization in Berkeley. Of course, we had the School for the Deaf and Blind on what is now the Clark Kerr Campus. That was a central--that school served the blind and deaf community across all the area west of the Mississippi. It had been here twenty or thirty years--maybe even longer like fifty or sixty years; forgive me on that, I can't remember when it was founded. But Dave got under a lot of heat from that lobby, from the parents and other individuals associated with the blindness group because he was spending all his time working with non-blind disability groups. He would actually bring to class the concerns that he was confronting: was he being disloyal to his blind community by becoming involved in this much larger community in which there were only a very few blind people? Was that going to dilute political resources and pressure that would go to the blind?

He made a decision somewhere during the first or early second part of his years there that he was going to work with CIL. But he also made the decision--because he was very bright, and I think it was under Wildavsky's influence, that he didn't want a career associated with the disability movement in politics. He wanted to be a foreign service officer. So while he was activist as a student, he made that latter decision his second or third year, and you could see him begin moving off because he was going to sort of play the straight academic game and not wanting to be labeled in that fashion.

While he was there, he was an extremely articulate and bright spokesperson and a key person, I think, in helping the wheelchair disabled begin reaching out to other kinds of groups in that time period. I haven't seen Dave Konkel in twenty years. I have no idea what became of him. Maybe you do. I remember him as sort of being a fascinating transitional student figure for trying to have the reach-out to the groups.

My observation over many years is that every time CIL wanted to reach out and bring in a new disability group, there was always some debate and conflict within CIL about whether to do the reach-out. Do you reach out to the parents as well as the disabled young people? Do you really bring in mental disability, which was a major, different set of concerns? I haven't been party to it, but I could guess that maybe issues

of homelessness or AIDS may have brought more recent debates in recent years, but I can't say I know about that.

Breslin: Look back a little bit for me and tell me your recollections about John Hessler, if you have any.

Collignon: Okay. John Hessler was at that meeting, the one I was talking about. John was director of the campus project before he went up to Sacramento with Ed. I can't recall any longer when John became head of the project, but in the effort to move the campus project into the community, John was there--to the best of my memory--throughout most of that kind of debate. John later wrote an article for one of the--was that called The Disability Rag back in the seventies, if I recall? John wrote a piece where he recalls some of this kind of debate; I remember because someone else sent it to me. John and I stayed, not close, but in contact during a lot of the later years. John was absolutely a major player. He never took any of the courses, but via the campus project he was a key player.

Breslin: Was he a student at some point or did he come in as a--?

Collignon: He never was in any of my classes, so I can't recall whether he had student status at Cal. I just don't remember any more. I remember a fellow who later went to law school here in a chair. No, no, he was applying to law school--he was a student, very bright--and got into UCLA law school, and was killed by a car, either while as a student or graduating a year later, while crossing the street. There were a lot of individuals in this time period. I don't remember his name any more, but he was another very bright and very articulate advocate, but he was also very much involved with what went on in the community. I remember as well, because given his law interests, he had a lot of interest in lawsuits as a way of potentially producing change. That debate used to also be made.

Breslin: Let me just also ask you--this is a question about your personal recollection and perception of the issues involving both the student program and the nascent CIL program in terms of serving people other than just folks who use wheelchairs. What was your own--given your politics and your background and your political science and public policy bent--what was your own hit on the issue of just folks in chairs, excluding or including blind folks--

Collignon: My belief was that it needed to be brought up in a broad coalition. You need to have people in chairs with other disabled if it's going to work.

Breslin: Now that's now retrospective. I mean, this is now.

Collignon: The goal was that it needed to not be professionalized, and it needed to have an attention to the wide range of different activities that a person needed to be able to cope with: housing, transportation access, employment, going out in the community. Among the debates we had early was, there was a lot less interest in the employment perspective here than often--I remember some of the discussions of the--I had an interest in employment because I was still involved with RSA, and that's employment-focused and by nature of having some economics background I was probably more interested in the labor force.

The image that often both the campus project and CIL were being--in those early years--deficient in their focus on employment. There was much more attention likely to be given to peer counseling, on how you manipulate whether it's SSI or other kinds of systems for the transfer check, and to want it to be much more involved in the larger political lobbying of issues, which was very important outside Berkeley than it was on worrying about people "getting traditional jobs."

Breslin: Why do you think that was true?

Collignon: I think because the politics was exciting for the folks. They had a chance to think of themselves as being players on much broader issues--these are young people getting a chance to be political advocates and having people listen to them, where usually you would probably have had to be fifteen or twenty years older normally to get policy makers to listen to you. So I think it was very exciting.

They were finding themselves with dollars and the ability to live in the community. They were finding Berkeley to be a very supportive community--I mean, within a year after that first federal grant the City of Berkeley, I think, contributed some significant money that we were able to arrange. Then I think a larger grant came in from the feds; it was more on the order of \$50,000 or \$60,000 a year. So they were finding a supportive city: they had some ramped streets already, and Berkeley was becoming a very attractive place for a person with a disability even to move to whether or not they worked on campus. A lot of things were jelling, and there were no other cities that I knew of where things were jelling as much as they were within Berkeley at that period of time.

The thing I want to emphasize--I am talking not about the role that the projects played. It's obviously the students and the folks like Phil Draper and the community who make this

thing happen. What is clear is that maybe it got some of the money a little faster because there were some campus research groups and the rest that saw this as a good idea and were able to make a direct link to Washington for them--and maybe find them a little TA. But I want to be absolutely clear, there's no way that "the projects" create--see, I'm not trying to say that at all, but I actually think it did happen a lot faster because the other stuff was also there.

Role of California State Department of Rehabilitation

Breslin: I think that's a fascinating observation, and I think that the relationship between the two is synergistic. They're essential. Tell me a little bit about--given your VR and rehab relationships and background and history--what do you recall the role of State VR in any of this from '72 or whenever? Do you have recollections of--

Collignon: Definitely we were also working with the state. The research project was working a lot of national issues, while also seeing the CIL model as something we wanted to support--and was working on the '73 Rehab Act. It had some larger things it was to do like create a benefit-cost model that would pass academic muster, and that was the official rubric under which we were getting some of our grants. We did a working paper series that had eventually maybe thirty titles in it, and annually we would send out the list of titles to all fifty states and urge them to subscribe. Forty or more of the states probably would buy them every year. We at least were getting our papers into the rehab agencies.

With California, we did a couple special studies that they had in that time period. I can't remember which was which. But I know that we would go up to Sacramento and try and--my impression, and I wish I could say that--my early memory was that California VR was indifferent to the independent living effort. Their biggest frustration, and it lasted throughout the seventies, was that the campus project to which they had given money, was not producing closures and disabled students going into jobs the way they wanted. That drive toward the traditional employment closure was the main thing that they were concerned with in this early period. So it's not that they were hostile, but they were not, as I remember, supportive of the independent living thrust.

If they thought they could produce some extra rehabilitations under their job-oriented system, they potentially had an interest. But I can't remember at what point money, if ever, started coming into CIL from the California agency. The students themselves had a lot of personal bad memories of California VR because invariably they would push the student not to go after what the student had a personal interest in as a career but something they thought could get the student through fast and into a clear job. So the students individually, from all over the state, would come to Berkeley with a lot of bad memories of VR and feel pushed by VR all the time they were there.

We did find some very sympathetic individuals in the VR system--I remember Herb Liebowitz from way back when being one of them, and there may have been one or two others--who we could create the rationale that if a graduate got a car, it meant they were more likely to be able to be employed. So adaptive vehicles VR would pay for, which was very expensive, and about every two years the state VR would say, "This is outrageous that you're spending all this money on adaptive cars." But we had friends in individual VR offices who helped us in spite of what may have been the overall friction at the top.

I remember an infamous weekend. There was some conference of the Employers for Handicapped statewide [Governor's Committee on Employment of the Handicapped]. Is that the one you're thinking of?

Breslin: [inaudible]

Collignon: Bob Metts and some other people that were involved in probably CIL by then--they were students. After the employers on the statewide stage had gotten up and talked about what a disabled person would need to work for them--and it was dressing right and cleaning up and being to work on time--the students from Cal thought that was insulting that they wouldn't know how to do that. Maybe they also said, "Why shouldn't I be able to come to work and not conform to your ethic?" At a statewide conference, they read out as "insensitive and unconcerned for the disabled" these presidents of manufacturing firms who had given a lot of their time to the governor's committee and in their minds had done a lot for the disabled. And it was a huge brouhaha. "Who are these arrogant kids from Berkeley that don't understand what the industrialists have given the disabled?" It just was atrocious. The governor was furious--that was the word that came down. Chuck Cole and I--Chuck was there--we made a personal visit to at least one and maybe two

of the industrialists who had felt personally insulted, trying to explain the nature of--"Well, students will be students, and it's a much bigger program than that. Yes, it was awful that they didn't have enough good sense not to read you out, to try and mollify their anger," because the industrialists were saying to the governor, "Kill the Berkeley program."

Breslin: Do you remember specifically who you met with?

Collignon: I think it was in the San Jose area. But I'd have to go back and look--

Breslin: Too early for the Silicon Valley groups.

Collignon: No, it was a more traditional industrial kind of group. But it was very scary, because we had the sense that the governor--the word came down that the governor was seriously thinking of ending whatever dollars were coming from the state to the larger group of programs, and that we might have no linkage to the state--obviously this is prior to Ed becoming head of VR [chuckles]. But it was a very problematic moment, and the reason we took Chuck--besides the fact that Chuck at that point was like one of the liaisons, spending a lot of his time working with the off-campus programs, CIL, and the other students--was that Chuck could be a student and be seen as older, so you could say that not all students had this. Chuck had some health problems, so we could cite that as an issue. Chuck was a fortyish-year-old student. He was a very old student by comparison. He knew how to play the game. So anyway, they cooled off.

I remember having Bob Metts in, and talking about being smart in your politics and in your public statements so you don't create wars that you don't really want to fight. I'm sure from Bob's point of view, you stuff the old faculty members who are trying to hamper what I'm trying to say. I'm not sure we ever succeeded with Bob Metts to create some sense of where and when you do your battles and choosing the battles and not worry about this kind of battle.

Breslin: What time frame was this watershed moment in terms of--

Collignon: Well, I do remember the moment. It's just I hadn't thought about that moment in twenty years.

Breslin: You can't place it?

Collignon: Assuming it's before Ed took over, so when did [Edmund G.] Jerry Brown [Jr.] get elected the first time?

Breslin: In '70 or '72?

Collignon: No, it wasn't that early.

Breslin: Really?

Collignon: Maybe it was '74 that Jerry Brown got elected. We arrived, and [Ronald] Reagan was being reelected the year we arrived, because I remember that I saw Reagan's speech on TV for the first time, and I said, "The guy's scary." And I disagreed with everything he said, but is he good on TV. That would have been the Reagan/[Jesse] Unruh race in '70, so it would have been '74.

Breslin: So it would have been '73 possibly. A busy couple of years.

Collignon: They were. We were doing this larger project, and I got into trouble--and in fact, I've always been in trouble with the university; the university had generally not liked my disability work--and the issue was I'm in the city and planning department, a little disability is fine, but they've always wanted to see me do much more traditional urban policy stuff rather than disability, and it's already starting at this period of saying you're spending far too much time on this type of issue, which is not seen as central to my department. So yes, I know I spent a lot of time dealing with the early warning about doing this.

There was another moment that's real important that Hessler wrote about, actually, in The Disability Rag. As the national legislative debate was perceived, what we were doing in the classroom was people would talk about what they would like to see in national legislation. We also did a piece about what the values ought to be that should inform rehabilitation, and those are the documents I was saying, if I could find, I'd love to attach. And then I would take them back and in Newman's office we would kibitz around. Other players in the Mafia were guys now in California--Jerry Turem, and Jack Noble was part of the early Mafia.

Breslin: And these are--

Collignon: These are not disabled; these are people back in Washington, just sort of career--.

Title VII of the Vocational Rehabilitation Act of 1973

Breslin: These are RSA--

Collignon: They weren't in RSA in this period where we recruited. In fact, I helped recruit both of those for Newman to RSA. The students were coming with this piece, I'm doing the write-up and taking it back to Washington as seriously part of what's being debated as our strategy. But during the writing of the act, there was this moment when the congressional committee is trying to decide how to write what became Title VII. And--

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Collignon: Okay, we're talking about the influence of some of the activists in CIL and the campus project on the '73 Act, and I don't remember whether it was called Title VII at this point at all. But there was a part in the '73 Act that authorized demonstration monies for what at least became independent living--and may have used the word independent living at that point. The debate in the congressional committee was, Do you write it like the Texas model or do you write it like the Berkeley model?

Breslin: And which committee was that?

Collignon: Whichever committee had the lead in the House [of Representatives]. Newman arranged that the committee should contact Berkeley to get the kind of language that would allow the Berkeley model to receive dollars--not that it would be uniquely Berkeley getting the money, but around the country, should other ones arise such as out of other campus programs, et cetera, that they would be authorized for the demonstration money. The congressional committee called us, and we arranged for some of the activists--including John Hessler in particular--to brief them and to suggest language. And for John it was always one of his proudest moments, and he really describes that in The Disability Rag article. He wrote that in response to--I guess there were some folks on the congressional side that said, "Well, disabled people weren't involved at all in the writing of this act. We uniquely did it out of the committee."

Remember I talked about a thousand people have to write every act? Fine. Newman was working that committee to help them think that they were innovating. When Hessler wrote his article, he said, "Wait a minute, you guys. You guys called us, and we suggested the language, and you put that language in

the act. I recall it directly." And he was responding to some other congressional staffers' view that no disabled were involved, and reminding them of the Berkeley activist groups' actual assistance to them in writing that piece. It was absolutely clear the language that went in finally was open to the kind of disabled-run independent living organizations as opposed to the halfway house approach.

Breslin: Do you have a recollection of specifically what section of what title of the act was amended?

Collignon: If I got the act I could probably see where it was because it was very clear at the time where the language was. I don't know whether Hessler in The Disability Rag piece actually cited the place. The original '73 Act simply authorized demonstration money. It was a subsequent revision of the act that actually created a section for independent living, which is Title VII. Title VII came later--I think it was '76 or something like that. But this was the original demonstration money.

Once they had the demonstration money, Berkeley got its second--Berkeley's first grant was, I think, prior to the demonstration money. Newman found a way of getting them some money to start up stuff, and then they got a regular demonstration grant, I believe, under the provisions of the act. But again, the point was not uniquely to allow money to Berkeley; it was to allow money to programs like Berkeley. And Newman was extremely committed to seeing the Berkeley one work from the beginning and to try and see other groups like Berkeley formed. So he was a very key player in making this happen. It takes a lot of effort and a lot of energy from people that have never quite done this before. It took maybe some assistance in thinking about it in a certain way--it sure helped to have a figure in Washington who wants it to succeed and is going to manipulate to get them some money to help make the thing happen. Certainly I view Ed Newman as very important to CIL whether or not CIL even remembers Ed Newman historically.

There's another point in a training grant that's important from the viewpoint of the CIL history. The idea of our training grant was to begin providing individuals training, not as counselors, but as policy people in disability. And we specifically wanted to have people with disability to get that masters in planning so they could go on to these other roles. People like Willsmore and Taylor actually entered the program, Metts entered the program.

Nixon Veto: Newman Fired, 1973

Collignon: The '73 Rehab Act, as you may remember, had an interesting Washington history in that it was passed with maybe one or no dissenting votes in the Hill and in the Senate, and Nixon vetoed it because it was fundamentally changing the program. It was launching the program off of a narrow employment perspective, and they literally caught the larger focus of rehab and independent living, which was the thing the president really didn't like. It was seen as potentially shifting and changing things.

In this debate, after Nixon was going to veto it, Nixon ordered Newman to testify against the bill. Now here's Newman, commissioner of the RSA, who has spent three years or more maneuvering to try and get this exact bill passed. It started very early in his RSA commissioner role. So the bill very much represents what he not only approves of, but has somewhat orchestrated very carefully through three years, and he's ordered by the administration to testify against the bill. He refused. He was hoping--I don't think he was hoping; I shouldn't put words in his mouth--some of us believed that his patron, Elliot Richardson, who of course later on resigned [as attorney general in 1973, when President Nixon discharged the special prosecutor during Watergate]. Newman was hoping that Elliot Richardson would be his defense mechanism with the president--not in this case. Elliot basically said, "You testify against it or you resign."

The Mafia around Newman argued, "Testify against it. All of us know your role in writing this thing and orchestrating it. But we need you to have the implementation of the act. And the reality is politics are politics. Newman took a principled position and said, "No way would I testify against this." He was forced to resign or was fired--actually I don't remember.

Breslin: Is that right?

Collignon: Yes. I don't remember which way it occurred.

Breslin: When? In '73?

Collignon: In '74, probably. Well, the act is officially the Act of '73, so it must have been in '73. And the bill was passed over the president's veto on the second vote, which meant you had to have two-thirds or 60 percent or something like that.

Breslin: If you would, I want you to go back and tell me a little more about the rationale for the presidential opposition--if the opposition was built on the idea that a demonstration program was created in the context of the Rehab Act for the IL [independent living] model as it was evolving here, and that's it.

Collignon: No, the larger thing was that this was a budget buster, it was moving away from--

Breslin: What's "this"?

Collignon: The larger bill. Remember the bill gives priority to the severely disabled. That's the fundamental shift. The logic in the past in VR had been that your priorities should go to the people most likely to succeed as a result of rehabilitation service. It was quite normal for the program to point out that severely disabled people would probably require more services and be more expensive and have less probability of succeeding in rehabilitation. The critique had always been that VR creamed--it went to the easiest cases to get them out, through the VR services--and still the VR creams within the context of the act. It was quite clear that the appropriate implementation of the old VR Act is that you were to get the most people through at the least cost and back into employment.

Focusing on severely disabled, which the '73 Act did, was a profound change in the whole priorities. It's sort of saying that--okay, we assume that a lot of these folks might get through successfully to employment without help. Let's focus on the people who are unlikely to make it without major services to the severely disabled. Once you agree you're going to give priority to them, then the issue may be getting the severely disabled through services who are most likely to benefit and succeed. But, the point was the priority. I think if we look at the national data, it will suggest a dramatic shift among disability groups and within disability groups over a period of several years to a more difficult kind of caseload in VR. So you're serving more difficult who may not succeed.

Secondly, you--I remember specifically, and at least Newman was telling me, the section that began opening the door to independent living and the rest was among the issues the president was citing. But I think the priority for the severely disabled was the one I remember the most, and the argument was that this was going to move this program away from an employment focus to a broader focus, and that was seen as less desirable.

There was other language in the '73 Act that's talking about aspects of the life of a person with a disability, which are not simply employment. They are talking more in general about rehabilitation and even habilitation for the mentally--no, habilitation was the second act. But there were broader definitions of employment in the Rehab Act of '73. And it was that doing away with the employment focus, focusing on severely disabled, that was seen as going to cost so much more money that Nixon opposed it. I don't think he ever opposed the principle that the act was doing. The argument was the budget part, and the budget part was there because of this broadening of the direction of VR. All that's got to be on the record as the language he actually used to Congress when he was fighting it. My memories are more the straight discussion with Newman at the time.

Emotionally I remember this at the time because at the point Nixon vetoed and Newman was fired, it was a real down day across the people in my research projects. And we had something like twenty or twenty-five people that were employed in the research projects. The project was safe, but we had failed. Everyone was doomed. I remember emotionally giving a talk and saying, "We're not going down; this is going to win." It was a rhetorical speech you have to give if you're running a large group of people and they're all down. It was a very emotional speech because for the most part it was simply my brazen self-confidence that was saying now this was going to make it.

At that point we didn't know that the two congressional bodies would overrule the president. It was passed over the president's veto. But what then happened is that you get the Act passed over the president's veto, and for three years he still had acting commissioners to block its implementation. I think the political phrase was "impounding" of money. I think that was the phrase. Never heard the word prior to that. But the rehab case was the test case of, could a president avoid implementation of an act passed by Congress? It was the test case. None of the congressman, the political scientists, or the lawyers were thinking about disability; they were thinking about the president's power versus congressional power.

The president's way of not implementing was to have no commissioner--only acting commissioners--on the grounds that they would not have the power to write the regs. And the way the regs eventually got forced out were by the disability demonstrations. Remember they did the three demonstrations in Washington, San Francisco, and--I can't remember if it was New York or Boston. The disabled sat in at the regional offices

and all the rest, and it was a very big moment for those people because it forced the issuance of regulations. There were some draft regulations that finally emerged toward the end of this, but it took those sit-ins and [Secretary of Health, Education and Welfare Joseph] Califano then saying, "Wait a minute--how are we going to deal with this very embarrassing situation of carrying people out of their wheelchairs and out of buildings to put them in jail?" that forced the issuing of regulations. That's probably '76 or '77.

Breslin: The signing of the 504 Regulations was '77. But let me bring you back again to the '73 Act. The firing of Newman must have had very significant personal meaning for you, not only because of your enormous sort of financial ties to the department, but personally because he had been such a mentor--or a colleague, or a pal. How did that play out for you?

Collignon: One, I was emotionally concerned for him as a friend. But it was a cause that he and I were working. I had the advantage of being much younger then. There are things that I now know that I should have been worried for him for that I didn't know about him. At this point I'm still probably in my early thirties; I'm confident that I can roll with anything and do new things. But at this point he's in his mid or early forties, and it's a lot tougher to find that next major role, particularly if you've been fired by the president. I don't think I had the sense of how tricky it could be. I mean, I felt sorry for him because he wanted to implement the act, and that's why various of us were saying, "Roll with the punch." We now well know it was a very principled act on his part. Even then I was prepared to be very Machiavellian, because the concern was how to get the thing implemented in the right fashion.

But it wasn't just me; most of his colleagues in D.C. were saying, "Roll with it; it happens all the time. Don't worry about it. We in Washington understand the politics." Newman's a very principled guy, and I admire him greatly for it. In his subsequent career he went to Temple University as a professor--he was a dean there for a while. He spent a good part of his career helping redesign the Israeli rehabilitation system. Very strong Zionist feelings on his part. So he rolled with it and did extremely well. But in fact it was a lot more risky step for him even then than I even began to imagine. Plus, I'm in Berkeley, right? I'm an activist Democrat, to be fired is a sense of disgrace. So in that sense I felt for him personally, but I don't think I had the larger sense of the huge career risk he was doing, because I was so confident that he was so talented that he would come back easily.

My memory was that I was much more concerned for the cause, that the bill might not get implemented, or would get fundamentally implemented in a wrong fashion by someone who didn't approve of what was going on. And if you look at the acting commissioners that came in, they were all fine individuals, but they were not reformers.

Breslin: Let me try to get at the question that's been on my mind since you've been talking about the amendments to the Rehab Act of '73. For the disability community, the '73 Act is a historical demarcation. It was extraordinarily important symbolically, practically, and legally.

Collignon: I do believe none of us in D.C. understood the implication of the accommodation--

Breslin: I don't think anybody else did, either.

Collignon: --contracting procedures.

Title V Civil Rights Provisions

Breslin: My specific question--recall if you can, in talking about the enactment of the '73 Act, which is really an amendment to previous acts--what discussion, involvement of students, personal participation--what of any of that do you recall in relation to crafting of Title V?

Collignon: Title V is which one?

Breslin: It's the one that contains the civil rights provisions, the one that contains Section 504, the one that contains the antidiscrimination provisions, which was--

Collignon: In hindsight, the key parts.

Breslin: Can you distinguish that from any other part of the process of the amendments?

Collignon: Let me come back to the issue of the students. In class, [inaudible] the direction I wanted the program to go. It included, as I recall, priority for the more severely disabled; that was very much there, as well as the independent living emphasis being in there. I don't remember, but if we did, it would be in that piece I wanted to attach. That was the piece that literally we all talked about in the research

group and in the class. I wrote it up, people reviewed my writing, I took it to D.C., it was discussed in the Newman office by those of us trying to think through various strategies. Newman liked it; he later said he used it--who knows whether he "used" it, but I certainly think the ideas per se became part of what was also influencing, and they were national ideas; they were things he bought and liked.

I just don't remember the civil rights part, partly because I'm not a lawyer. Some of the aspects that could have given greater clout I wouldn't have known, in the sense that you could have sued on it. My perception for ages had been that the first point in which you really--you got civil rights law protection, which was more the ADA [Americans with Disabilities Act] rather than the '73 Act. What you got was the ability to sue on procedure, I thought, with regard to government contracting if you didn't provide certain benefits and rights to the disabled. But you still didn't get the larger civil rights protection of society until '88. Is that not the case?

Breslin: The '73 Act established Section 504, which barred discrimination in programs that would seek federal funding.

Collignon: Right. The contracting part began--

Breslin: No, actually that also was established in Title V as a separate section. But the provisions of 504, which were codified in the regulations and were signed into law in 1977, the basis for all the demonstrations, sort of contained the provisions which became the ADA. But we don't have to discuss that here.

Collignon: It seems to me you still delineate that--you got nondiscrimination rights as you were contracting with state and federal government. You didn't get them in general in society until the ADA.

Breslin: The only difference is that the protection didn't flow from contracting; it flowed from the distribution of federal dollars from federal agencies to entities as well as contracting.

Minority and Gender Issues

Breslin: Given that it's quarter to eleven, and I know you've got to be back, I have one--while we're sort of on a roll here and while you've got this in your head, let me ask you one other question

about the student group and your recollection of those two or three years that were really seminal periods of time. Do you have any recollection of issues having to do with minority disabled students? In particular, were there minority students participating in any of the discussions, any of the strategies, any of the issues that were raised in your classes?

Collignon: I definitely remember that there were at least one or two discussions that emerged in class about if you really wanted an umbrella group, what needs to cut across ethnic groups? The problem with that point was that no one could identify, I believe, any minority disabled who were then on campus, so they didn't know who to reach out to. And I didn't know who to point to--to help to bring John in; I didn't see any Johns around that were black or Hispanic at that point in time. That was always seen as somehow this potential weakness that was out there, but just trying to get the different disability groups to work together was a big enough deal without worrying about the ethnic issue.

The gender issue fortunately didn't emerge. At the beginning there were some very strong women like Judy Taylor who were involved. Somehow people weren't worried about that. There were a lot of reactions--I remember Judy would come in and talk about the wheelchair men being male chauvinists in the worst possible way [chuckles]. The feminist issues were certainly out there, and I know they talked through those. But the fact was that there were women that were involved that were in leadership roles.

Breslin: Do you remember others besides Judy?

Collignon: I suppose about three or four years ago, I found a file that was my major reports from that period that had--ones that you had to give back to the government, and which had to list all the students on the research project. Unfortunately, I think I heaved it at that point, which would have at least given me the names of those that were students. Judy I remember best because she later became a graduate student in the program.

Breslin: I was asking the question because her name is of course very much associated with this period of time. The majority of other students are men, and I was hoping to hear that there might be other women who had disabilities being involved in the period.

Collignon: I don't remember it being an issue. I remember the discussion with chauvinism, but I don't remember, in any event, it being a big issue at the time. And I do remember the image was it's

tough enough dealing across disability groups that the ethnic balance could come later. And the reality is the university didn't in particular. It's not the university it is today, where only 35 or 40 percent of incoming undergraduates are white. The university itself had very few blacks or few Hispanic students. And the Asian students may have just been arriving in large numbers.

There were one or two student papers about the handling of disability in different ethnic communities. I also occasionally raised--I remember coming back from Hawaii somewhat shocked because of what I heard in the Hawaii agency that Asian families would invariably not come in for services--that it was such a disgrace that you would hide the person with disability in the home--and you wouldn't think of going to a state agency for services. Obviously my experience was very limited at that point, because I just remember being shocked at that kind of a cultural tradition. It was definitely this sort of routine line by the Hawaii agency which had numbers of Asians in the agency in management positions. So, you know, I said, "Gee, there may be a larger tradition that was here."

Years later, I did some stuff for the Buck Trust; we tried to set up a manufacturing firm uniquely aimed at hiring disabled people. Not a workshop, but a freestanding, regular wage-paying industry that had its focus on disabled people. The Buck Trust was prepared to put in money. I guess there was one prior model in the U.S., in Minnesota. Eventually, it didn't fly, but the focus here in part was also to have individuals with mental illness history work there. I remember going over numbers for Marin County and pointing out to them how very few blacks they had in the client loads in Marin County. This is strange; I mean, I know that the major black area is Marin City, but I still didn't even see in Marin City any blacks. And the phrase came from the director of mental health in Marin County: "The black community has other ways of coping with its disabled members." My jaw dropped and I said, "What's going on here?" This is Marin County in the early eighties or so. I tried to get her to talk about what she meant, and she implied that the churches and the services handled it, but in any event she had no desire to worry about a special outreach to other minorities.

So whatever the problems were, they were not uniquely disabled people in their prejudices; it was a prejudice that I thought went up through all the system. I did, or our projects did, a couple of papers--I actually did one for states back east, Maryland and the rest--that documented clear underrepresentation of blacks in the disabled caseload of

states in contrast to populations, where if you assume poverty is highly associated with disability, one would assume that--poverty being more represented in some ethnic groups, there should be a larger representation of population--clearly they were underrepresented. So I would say it was probably a national problem in the disabled services community. We were not, perhaps to our insensitivity, pressing the issue at that time, as I remember.

Breslin: That seems like a logical place to stop for today.

[tape interruption]

Collignon: Chuck Cole spent a lot of time working with CIL and these groups, and his dissertation was unusual; it really combined three separate dissertations in one, despite listening to me saying, "Chuck, you don't need to do three; one's fine." One of them is a detailed history, probably written by around '73 or '74, of that period of organizing, where he's actively involved and he's trying to take himself out of it. One of the things we tried to do was to try and take Cowell out of the focus on what the disabled community did among themselves. But you might find that one interesting. He's got an analytic part, he's got this history part and--of disabled people, of giving them the invention of coping technologies--you know, put some academese on some of this stuff.

Breslin: Let's put it on hold to discuss the next time, because I do have some specific questions about it.

II MOVING FROM A CHARITY MODEL TO A SOCIOPOLITICAL MODEL

[Interview 2: April 2, 1997] ##

Charles Cole Dissertation and Social Technology

Breslin: Fred, we concluded our last interview talking a little bit about Chuck Cole and his dissertation, and you were his dissertation committee chairperson or advisor. I know that this was a big project. Could you tell a little bit about how that came about and your recollections of Chuck and the project?

Collignon: Sure. In the Disability Center, as it was called in Washington--although it was not formally a center as the campus calls "centers"--[inaudible] there were four or five grants that were being housed. Chuck was one of the oldest of the grad students. Chuck had come back to do his doctoral studies at a relatively older age; Chuck may have been in his late thirties, even early forties, when he came back. He can't have been that old--but he was much older than other doctoral students, and in terms of years of experience. I was also just arriving, so Chuck was probably a little older than me at the time we were there.

Breslin: This was '73 when he began?

Collignon: The first grant came pretty early: in '70 or '71, but the larger grants came around '72, and we stopped the center here about '76 or '77. Chuck, being a doctoral student--and older--became a lead figure. We had some fifteen to twenty graduate students that were employed in the Disability Center research projects, of which there were probably about seven or eight doctoral students. Chuck, being senior and having lots of governmental experience and a lot of interest in disability, was definitely a leader in it. He was in that very first court that focused on disability, that produced the study of training programs for counselors working with the students with

disabilities on campus. And it's probably true that the study was a bit more effectively drafted in styles that government people would read, because Chuck was an old government veteran who would know how to help the students do that. It's clear, I think, it was not just any doctoral student; he was someone who kind of knew the ropes of government and who could help them prepare it that way.

Breslin: How is it that he had experience? What do you remember about his background?

Collignon: I don't remember it at all being necessarily in--well, it certainly wasn't in disability programs. My imagery was that it was something like in water reclamation or something. But he nonetheless had a very strong interest in this area from the beginning.

Chuck took a bit more time to finish the dissertation than some do, but he wasn't like one of the ones who took forever. He got himself very much involved with our research project, but also working with the students on campus as they launched CIL and helping them in doing that. To the best of my knowledge it was all volunteer efforts on his part, but I think he was on the board for a period at one point, and he was certainly very much involved in our, literally, our strategy. We paid one of our staff to provide ongoing counseling as they needed, which was Barbara Thompson. But we also knew we had some others like Chuck, volunteering extensive time.

Chuck's dissertation ended up being, in my mind, three dissertations rather than one. Any one of them could have been a dissertation, appropriately. That's why it took him so long. The first was a fascinating history of the rise of disability politics and movement in the West, dating back to the movement that gave rise to the deaf/blind school on this campus--the first such program west of the Mississippi--and then continuing forward into the CIL movement. It was a wonderful history. At the time, maybe the first fifteen years, it was almost the only such written history of that period, and one that showed that CIL didn't just arise *de nouveau*, that it really was grounded in a much older history of activism that involved this campus--particularly the deaf/blind school as being a major example of that, which I think the current disability movement often forgets, that there was that much earlier history. I can't remember what those times were. I don't think it went back as far as turn of the century, but 1920s or so?

Breslin: You're thinking of ten Broek's contribution to that.

Collignon: Right. There was another section of the dissertation which was a more quantitative analysis of the effectiveness of VR program agencies. At the time, there were only one or two other studies in the field. It was very similar to the kind of work that BPA was independently doing under federal contract and did a number of times in subsequent years. A kind of regression modeling of the state program, but also of individual records to analyze what worked and what didn't work. At one level that could have made him in a different circle; it probably would have helped if it had come out a little sooner. His access to those data emerged from other studies that we had done. Again, it was good, but it wasn't quite as innovative as if he had brought it out a little sooner in time.

The third part was a fascinating study of technologies and a look at social technologies in contrast to what we more normally think of technology as being hardware and science techniques. Social technology is the ways in which people learn how to cope with life and to cope with bureaucrats and to cope with other people in society. I thought in fact that that was an extremely penetrating observation, a very important concept. And I've still never seen it out there. It was very original. Any one of those would have been a dissertation; he had to do all three, which is why it took him long. And the sadness to me--I kept urging him every year, then it was every other year, then every three years, "Chuck, you've got to publish some of this!" To the best of my knowledge it only exists in the dissertation in the UC library. He never published any of it. It was really sad.

Certainly the two that were more "qualitative" are both still very unique contributions to knowledge. The quantitative one--I mean, there have been many such studies, but it's still a very interesting benchmark study if you were to want to see where things were in that time period versus later time periods in analyzing VR programs. I would say we had about four or five dissertations that were issued on disability, by people who later went off to the Rand Corporation and Urban Institute and elsewhere, but I think, number one, that it was the most grounded in the history and conceptual thinking about disability. The others tended to have much more focus on program analysis and yes, they were analyzing disability rehabilitation programs, but they could have been analyzing childcare or manpower programs, and the real interest of the dissertation was on modeling or cost benefit or cost effectiveness. The person's interest on the way they later lived their lives, which was really program analysis and planning rather than disability.

Chuck was very much interested in disability. The sadness to me was that he never was able to get the kind of academic placement in one of the disability research centers, and I've never been quite understanding of why that occurred. Here's this fascinating dissertation coming out from Berkeley. Part of the problem was that Berkeley was not in the university rehab net; most of those were unfortunately not first-year schools, the way Berkeley was. It was not the network of contacts and people--there were different professional associations that Chuck was in--and I know he applied for several, and he may have been a finalist for one or two to be even a director of an R&T center. But it never happened for him. So he really went off in other lines of work. I always thought it was sort of a great tragedy for the rehabilitation field.

Breslin: Do you recall whether the dissertation had an impact on students and on people who were beginning to think about forming the student program here and the Center for Independent Living?

Collignon: Certainly the completed dissertation, because it came out belatedly in that context--Chuck's thinking may have very much had some effect. But the student program at Cal was formed a couple of years prior to Chuck's arriving here. Chuck arrived here in 1970, I believe. So it's a little bit after the campus project for students with disabilities got launched, and CIL was launched also prior to the issuance of the dissertation. I can't judge the extent to which any of his interaction with other students with disabilities he was intellectually influencing. He certainly was interacting with them a great deal, and he was providing--to the extent they wanted it--a larger conceptual framework. I can't claim to know that that was influencing people.

Breslin: I was very interested in having read that dissertation recently, that it was very much on the cutting edge not only for its time but even now.

Collignon: Two of those three parts still are.

Breslin: And it was very curious to me whether people here adopted in some way or another the points of view and the perspectives that he included in the dissertation. It sounds like maybe, maybe not.

Collignon: If it did, I would say it occurred more with the students with disability who he was working with, rather than the rest of the students here. But the department, being the department of

city planning, had a major thrust in social policy, which is where this whole program was launched. But the department was going more in the direction of policy analysis, but wanting it hard, and Chuck was going both ways: hard quantitative, but also qualitative. Most of his other Ph.D. mates were going in the quantitative direction at that time. They were doing fascinating work: big systems modelings of how the VR system operated and similar things. But I thought Chuck, of all of them, had the most intellectually provocative understanding of things.

Breslin: Did you and he have conversations about those theories?

Collignon: Sure.

Breslin: Can you recall any particular directions that were interesting to you?

Collignon: When you're advising students, in those days I saw my students even more frequently. I've now supervised forty or more dissertations. I can't remember the conversations, but certainly I thought it was original of Chuck, this distinction on social technologies. I've been very fascinated by Donald Scott's book, Making a Blind Man, and certainly was making everyone read that. I can't remember if I had it in draft copy at the time as opposed to a book copy. It was into the question of how society creates the self-construction of blindness among blind people. That broader understanding of-- now there's a whole postmodernist retrospect; I don't remember what that was called--was 70 percent of what both Chuck and I were deeply interested in, and probably more so than a number of other students that were in the program at the time.

Again, there were some other students who were involved in disability in part of their lives, but in fact their dissertation was in quite a different area and nonetheless went on to disability careers. Sue Stoddard was in this program at this point. Sue's dissertation, though, was an analysis of voucher programs for childcare, if I remember. It was not disability-related at all. Sue has made a significant part of her career in disability and has done excellent, excellent work for many years.

Breslin: Donald Scott's book that you just mentioned, do you remember roughly the publication date on that? Is it mid-seventies?

Collignon: I would assume it's mid-seventies or early seventies. Princeton University Press, if I recall.

Breslin: And you mentioned that he suggested blindness as a social construct. Was that consistent with the point of view that you and Chuck and others were thinking about?

Collignon: Well, I certainly believe that disability was a social construct. And the intriguing part of Scott was that it was not merely that other people were trained--or society helped other people view that something was a disability, a handicap--but you could get the individual who had the trait to believe that it was a handicap as opposed to a disability. No one put this in postmodernist language or philosophy of knowledge at the time, but to my mind that was a very powerful observation.

In contrast, there was a very important article by Donald Schon, who is what you would have called one of two professors of social policy at MIT, in planning. Donald Schon is an esteemed national name. I was the junior young buck in Berkeley--Berkeley is the main rival of MIT for number one ranking in schools all these years--but a number of folks have graciously said that sort of I'm most like Don Schon here at Berkeley. It was intriguing because Don Schon's article--it was the only article he ever did on disability--came out about '71 or '72 in the journal Public Interest, a journal of public policy commentary. I don't remember the name of the article.

He was focusing on looking at the blindness system, and he treated it as a non-system; the key to it was that it wasn't organized, which was the opposite idea of what Scott had and certainly of what I think we had. We perceived it in fact, rather than being a non-system, it was highly systematic in ways that did not simply include routine governmental institutions. It included practices, social definitions, professions that were shaping this. But it was not uniquely a system that you model uniquely of governmental agencies or even their interactions; there were so many other things that were happening in this state that it was emphatically systematic in the way it created barriers and the way it created self-consciousness on the part of the person who had a physical impairment, but also in society and how they interacted. I've always been intrigued; I looked at the same phenomenon and came away with a very different understanding of it than Don Schon did. Don Schon is one of the most brilliant, most provocative people that I have ever read. I stand deeply admiring. It's just that in this one I think he had it all wrong [laughs].

Breslin: Any thoughts about why he had it all wrong?

Collignon: I actually tried to do a little understanding with folks like that, and once at a conference I got to ask Don Schon, "How do

you do that?" He basically sort of spent a month or two during a summer happening to be in the Washington agency that did blindness, and observed. So his perspective was to say, "Was there a system from the viewpoint of where government was operating?" and that missed the much more complex stuff.

I had a hard time getting my own ideas on this. I remember the first lecture at Cal, in fact it was a disastrous lecture. Not the first lecture; it was the first lecture once I was professor. Fortunately my dog-and-pony-show lectures were fine. I tried to give the faculty a model of how the disability rehab system was operating. It included the government agencies, it included the state CSAVR directors, it included the professions, it included a bunch of social institutions, the nonprofits, the disability lobbies. But the point is I was doing it as a reaction to Schon, to say here's how the system works. It was deadly boring. If you weren't in disability you could care less about that aspect. I remember two faculty saying, "Fred, was this important? Was this innovative?" I wasn't helping them understand that this was intellectually challenging Don Schon.

There was a reason. Stupid me, I didn't want to start off at the time saying "Don Schon--" this one little person who people are hoping that maybe I'll do work in that tradition at Berkeley--"has said this, and I think he's diametrically wrong." I didn't want to take him face on. So I tried to do it, but, therefore, didn't give my fellow faculty members a context in which to think about it.

They would have been bored anyway, because they weren't interested in disability per se. But I still remember the disaster, and I've often later said, "Okay, what was I doing?" I knew I was trying to do it in juxtaposition to Schon. I now know how to present a lecture like that that would have kept it much more interesting, but back then I didn't know enough to know how to do this. I should never have presented that theme to my faculty colleagues; they weren't interested in disability. The issue of whether there's a system or non-system is not nearly as intriguing unless you're trying to make policy change within that system.

Breslin: It sounds like you were also working out your own analysis at that stage about what the fix might be in terms of social policy solutions.

Collignon: Absolutely.

Breslin: It wasn't entirely cooked; you were still processing--

Collignon: I had started, as we had said the last time, in that activity with Newman where I had a chance to go out and interview all those state people and the rest, but I was still being amazed at the power of the disability lobbies. The deafness and the blindness lobbies were just amazing to me, because you never would read about them. And here they had huge impacts on policy, but they were not the kind that were ever being formally noted--even by the state VR folks--they had to know they were there in dealing with them.

Disability Lobbies

Breslin: Tell me about the lobbies as you remember them. Who lobbied? What was the nature of the lobbying process?

Collignon: My favorite example is always--you have the Randolph Shepard Act that created the vending stands. Blind people got to run the vending stands. They were extremely lucrative in the federal buildings. Those blind people usually were major players in the blindness associations in many of the states. They would both lobby to maintain the vending stand program, that it would be reserved for the blind, but also they thereby helped create an ongoing blindness association that would be there working with select legislators to write the legislation that would affect blindness--to make sure that blindness programs would not get integrated into general VR programs. Lots of states--would be reformers maybe to save money, but often for social reform--would want to see them more integrated because there was very little vocational emphasis on the blindness program.

These were very important functions. Teaching a person how to live with a dog or a cane or a range of different kinds of social adjustments that we would call habilitation, and much less on the rehabilitation side. The analysis also that we did has been very clear, that individuals with visual disorders were achieving jobs with far higher wages than individuals in wheelchairs or others. Somehow that impairment was far less disabling in terms of employment than people were often thinking. But they also had huge social control over their own members. And I think we talked last time about the student who went off to public policy--David Konkell--and the pressure they had on him not to try and work with the other disabilities. They wanted to reserve his talents uniquely to work on behalf of blindness issues. His stance that he wanted to break away altogether from the disability stuff was as much a matter of

his breaking with the blindness movement, which was putting this cross-pressure on him, as it was any desire uniquely to break with the CIL movement.

Breslin: Which raises another question about the division of services in many VR agencies in states, where the blind services were housed in one--because one strand of service--and everybody else got served by the other strand. Did you have any occasion to evaluate that process or to observe it or write about it?

Collignon: A lot of different states we did, and some of the BPA reports we took it on directly for some of the state studies we did. We would evaluate--the issue is, Were they as effective as getting people into jobs as the main VR agencies? On a total per-dollar basis, no. The difference, though, is they were often trying to do a lot of these other habilitation goals rather than solely voc rehab. They weren't trying to meet the employment goal. So separating out the dollars, to then focus on the dollars spent on VR--no, they were not as effective, but they also had in addition, don't forget, they needed to put people into work, period. They often had their own specialized sheltered workshops that they could use to get their numbers up.

Breslin: So were the blind services within VR more progressive than services to people with other disabilities because of what you're calling this habilitation function?

Collignon: Part yes, part no. In terms of employment no, because it was either you'll find it on your own or you'll get it in a sheltered workshop, as opposed to, "Let's help you get a regular job." Yes, they are more progressive to the extent that they were helping a blind person discover how to live in the community. No less progressive because they wanted to isolate the person within the blindness community--in the sense that you could be in the community, but you've got to stay among our grouping. It was less integrative than was the CIL philosophy at that time. CIL was looking to find peer support among other people with disability, but its strong goal was to get people with disability out into the regular community. It was demanding integrated transportation, for example--transit systems--whereas the blind would have jumped on the idea of running their own transit system, I'm pretty confident. It would have been very consistent with their separatist but equal, if you will, strategy.

Judy Heumann and the Voucher System

Breslin: Let's talk about your recollections of Judy Heumann and the first time you met her or how you came to get to know her.

Collignon: It's hard to say the first time I met her now. We were trying to think through how to link the rising disability movement in different cities to create a national--it was self-conscious, as you'll see when you read the documented plan. Judy Heumann had obviously done a lawsuit or what have you in New York. She, by everyone's statement that we had checked out, was an outspoken, entrepreneurial, ambitious, effective leader. We wanted her to come to Berkeley, and CIL wanted her to come to Berkeley.

Breslin: When you say "we" do you mean the department, do you mean the community? Who is "we" in this context?

Collignon: Those of us who wanted to create the larger national movement wanted her to come. Leadership people in CIL, I wanted her to come because I was trying to get the linkage to the extent that that was one of the goals that we saw ourselves as trying to help happen if we were to make changes in social policy. She was persuaded, more by CIL people, I think, to apply to the City Planning Department, because we're the ones that had all the dollars on campus. I couldn't get her through our admissions. Didn't have some of the laws that I could now go after to--but I don't think that was the reason. It was really more of a--while doing her wonderful work in New York, her academic record had not been spectacular. My department was very uptight or whatever with regard to some of those kinds of thresholds. But I was able to get her into the public health school. We had these training grants where we could recruit people to train them for policy and evaluation and leadership. And we used one of our grants and gave it to the public health school to support her. Years later, it became clear, Judy was unaware that this had happened, and that was fine.

Breslin: Is that right?

Collignon: That's what she said. I don't know how she could be unaware, but nonetheless--

Breslin: Did she tell you that?

Collignon: Yes. We talked about it; she just didn't have any understanding that that was where those dollars came from. I don't know whether she forgot or the public health school never

bothered to say. It's possible we never emphasized it, because frankly I was embarrassed that my department wouldn't admit her. Anyway, it was a surprise.

She came here, she took the main classes that we offered at that point. There was a basic class in disability. But because she was in public health, she didn't take a lot of our other program evaluation and policy analytic courses. So she had our course in disability policy. I think I may have said last time--I remember the debate we had in one of the classes I had forgotten about vouchers. My argument at the time was that vouchers would help people with disability to become independent of those rehab counselors. And Judy at that point was very opposed to them on the grounds that if you break apart the rehabilitation movement--I know she's totally flip-flopped with regard to that [chuckles]. It's just funny because I heard her give a speech, and I thought, "Wow, she's come a long way in those twenty years." [laughs]

Breslin: What is a voucher?

Collignon: A voucher in this context meant that you would provide the dollars--at that point the federal government provided dollars through the rehab system for VR counselors. We were saying provide a voucher for that same amount of money to the person with a disability to spend. They could buy from the VR counselor the service that they wanted or buy it from what we predicted would emerge, which were independent living centers offering a comparable service. Back then there really weren't any yet doing that, but we figured they would arise. Or if private nonprofits or profits came out there doing services, at that time there was not the big private rehabilitation counseling industry that there is now, but the change that came into play is fine. It would empower the person with the disability to choose who were going to be the service providers and what kind of service they wanted as they went after the goal of employment. Back then, state agencies didn't like it because they weren't willing to trust that the person with the disability would use it for employment. They could just spend it any old way they want, to go buy a truck or a van for their personal--

Breslin: Fly to Hawaii for the weekend [chuckles].

Collignon: Sure. So it was conceivable that you might have to put some limitations, that they had to be looked at as employment, but the point is an adapted van for transportation to work, to my mind, is employment serving. Transportation in a couple of our

studies appeared as the biggest reason why people who first were rehabilitated failed to hold the job over time.

Breslin: What was Judy's position in regard to vouchers?

Collignon: In the debate in class she was strongly against vouchers. And the reason I remember was not just because she later--it was a strong debate, and I said if I can't persuade Judy Heumann, who I think is going to be a major leader--is there something wrong with my stance that I can't persuade her to see this? I remember viewing it as a big failure on my part. I could persuade the other planning students that this made sense, but they had a public economics course--which I taught--and having had some of these courses, they were able to understand efficiency and all that stuff. But I saw this as much as a political tactic as I did as an efficiency tactic. By this point--maybe it was her second year; I can't remember--she was clearly now a leader within CIL, et cetera. I couldn't persuade the movement leaders, emergent, to buy into the concept.

Breslin: Tell me again what her objection was if you can remember it.

Collignon: The principal one at the time was that it could cause the breakdown of the entire legislative disability package they had that assured money flowing through disability people. Because after all, if the disability people got vouchers, well, maybe they would cut the vouchers over time, whereas probably they wouldn't cut it if it were going to an agency. That was the one big one. And secondly, some disabled people would be misused in the same way that sometimes people go in and they buy these flimsy--"go to my college and I'll give you a one-year degree and get you into this great job"--that that kind of thing would happen to people with disabilities. Some individuals with disabilities had a hard time then, because the independent living centers were not in place, which made better reasoning. I'm reading into that. We saw the independent living centers, even if they were not providing the service, being the vehicle by which you would help educate people with disability and how best to use those, and a source of information therefore to help provide wise use. The problem with the school voucher idea--it's an excellent idea--

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Collignon: The problems I've had with the way the school vouchers have often been presented to the voters is that they simply give money to everybody, and thus they can benefit more disproportionately the middle class and the rich. They also

don't provide an information base in place that could help poor people or parents which lack the education in helping choose schools and make the evaluation. That's the big gap. In fact, I think at that same time--well, I guess it came out later--Sue Stoddard's dissertation on child care vouchers actually made the same point--I guess it was a couple of years after that--that vouchers work very well for child care, for empowering parents. The main thing you need are organizations that can help educate parents about what to look for as they evaluate a child care center. And in this local area, that's what BANANAS does so brilliantly. My imagery is that the CILs would be the BANANAS of helping people with disabilities learn how to use vouchers, should the CIL decide they wanted to offer some of the services directly.

Breslin: Ask Judy her views now, her current positions, and see what she thinks about all of it now twenty-five years later.

Collignon: My impression from one speech is that she now supports vouchers.

Breslin: I think that's right. Judy was a student here--can you remember the dates?

Collignon: My image is that she had arrived around--she was in the last group of dollars that we had, so it was probably around '75 or '77.

Breslin: I think so. Tell me a little bit, subjectively, about your perception of Judy as an emerging leader here in Berkeley.

Collignon: She was smart, and she was very outspoken from the moment she arrived. She liked the Berkeley scene pretty early on, because it was supportive of an in-your-face style that she had learned and developed in New York. Instead of people finding it offensive, that was the style of Berkeley politics at that point. And it worked well. On one level you could say it was not the style of New York politics, but I'm gathering from others I know in New York, but not as readily, as certainly not in the disability scene. But in Berkeley that was the style, and it worked really well. So she came with a political style that was really effective. I would say she learned over time how to be more discreet, diplomatic--the politician part that was the politician in the negotiating room as opposed to the confrontation. But I think there was no question in the beginning that she had incredible leadership capability. My memory was that she was a leader within a year at CIL. Very fast acceptance as a leader.

- Breslin: Did she have a role as a student leader that you recall?
- Collignon: My perception now is that the students with disability--I can't remember--
- Breslin: It's only been twenty years [chuckles].
- Collignon: I really can't recall. It occurs to me by then that the students were actually putting more of their time in CIL than they were in the student project. But I don't know if that's right at all, as I think about it. I don't want to mislead.
- Breslin: They overlap, I think.
- Collignon: They clearly overlapped, it seemed to me, very heavily in that period.

Berkeley Planning Associates Formed, 1972

- Breslin: Let's talk a little bit about your conceptualization and founding of Berkeley Planning Associates. How did that come about?
- Collignon: When I was still in graduate school at Harvard, I needed to make some money to support myself to get my way through, as it turned out. I had a tough semester due to a broken engagement and some other stuff, so I sort of lost my fellowship. A group called Abt Associates was rising up and was very exciting. It had like thirty-five staff--very small--now it's gotten as big as 1500. They were doing applications of social science to policy issues. They basically were just starting a strategy of hiring grad students from Harvard and MIT to kind of be well-paid by the standard of the time folks, but it would give them twenty-hour days as necessary, seven days a week. I joined on and did well, and was doing regional economics in those early days. As I did that, it got me also into employment programs, and I would then recruit other people from Harvard and MIT to them. At one point, there was supposedly a Harvard faculty meeting that was complaining that their best doctoral students in econ were going off to these firms rather than taking the TA-ships and the RA-ships. Harvard wants that cheap labor. It was good pay by the standards of that day.

Anyway, I already went through, didn't I, how we had the work that got me and eventually Newman there? Well, I came here and was working, and I took a cut of over half my pay to

come to Berkeley as a professor. That was pretty dramatic, particularly since I was coming as a newly married guy. I wanted to do something consulting, so I initially did it for Abt Associates. I helped them open a West Coast office in San Francisco. I helped them do it, but I was still assigned to work for Clark Abt directly on national projects. But on the side I was asked for my help, and I did that. We had a break, unfortunately, over pay. I didn't view it as an unfriendly break; I don't know if Clark did at the time. Probably he did [chuckles]. I just viewed it as bargaining.

Breslin: It's business.

Collignon: Business, right. We had some faculty here, not me, the lead person of all folks I believe was Martin Krieger, who's now at USC. Martin was asked by the Army Corps of Engineers to figure out how to evaluate some new projects for doing tertiary and other treatments of solid wastes by shipping them out into distant land areas and blowing up in the air and letting it settle down. That was the aeration effect. The issue was, How would that affect the areas? Basically, how would you like a shit field near you? And would the community accept it?

That was a grant. People said, "Let's do this." I said, "Well, rather than do it as a grant, guys, since none of us get particularly paid very well doing it, why don't we do it as a firm? Let's see if we could create a firm." So I was the catalyst saying, "Fine, you have a grant, but let's not take it as a grant; let's take it as a contract." I persuaded four of my faculty colleagues. Martin didn't want to come. Martin didn't want to do the study; it was far too applied. He was theoretical in his orientation. We formed this firm, Berkeley Planning Associates, as five equal partners. I was the CEO from the beginning--I was not the original president. The original president was Michael Tietz, who went on to become the chair of the Academic Senate here. But after two years I also became president and CEO.

But the key to it working is that we had that one little grant, but I also that summer wrote three competitive proposals for contract competitions: two of them national, one for state. And I won them all. That's very unusual for young junior faculty. The key is I've been doing this--I've been the deputy area manager, and you've got to write proposals. We won them all. Two were on disability. One was in child abuse and neglect. All of them were large-scale evaluations. And then we had this small one on the Army Corps of Engineers. We formed the firm, and within three months we had at that time close to \$400,000 of money--\$400,000 then is over a million

dollars now. Unlike most firms, we started from ground zero and immediately ended up with large amounts of money, winning in competitive bidding.

Breslin: Five principals at that stage?

Collignon: Five principals. But then we're into this work, and it turns out that three of them are all uniquely stuff that I know how to do, or getting involved in disability. Child abuse and neglect, I had been working with a student in public health, Ann Cohen, on her doctoral dissertation. She and I had written this--I'm not sure if I've got my timing right. Yes, that was definitely one of the first. So we were doing this doctoral dissertation on child abuse and neglect on a very different project, and we knew a lot about it and we won this first national study. The first national evaluation they ever did. Well, people come a long way.

Ann Cohen became the first White House fellow ever to be selected from a private profit firm. Worked for a bunch of people, including a senator named Al Gore. She was the head of what is the largest national foundation for doing research in child abuse and neglect, has turned down all kinds of federal jobs including being chief aide to Al Gore in his vice presidential role, et cetera. She's a big figure in child abuse. She's been out of BPA fifteen years doing this. But she was with us close to eight or nine years. She left as a White House fellow and didn't come back. That's the sad part of becoming a White House fellow, but it was a wonderful relationship while she was there.

And we were a major firm: but a major firm also that was looking at disability issues, as a major share of our revenue and what our interests were. There were no other organizations in the Washington think tank or other groups for whom disability was a major part of what they did. When Abt Associates did a disability study--this was a little blink in the midst of all this other stuff. They weren't necessarily trying to keep people around with expertise in disability. We were.

We had gotten the studies because we had also done all this university research, so on the university side we were still actively involved. I decided, one, because of conflict of interest judgments of my own that we shouldn't be overlapping, and secondly because I was angry at the Feds that they were telling us in September or October when they were giving us money for students who were supposed to have started that September. We stopped doing disability research through

the university, and so I would only do other research through the university--not disability. I would only thereafter do it in the firm. But we had lots of students who had done disability work, who as they graduated came into the firm--and while they were studying they also worked with the firm.

Breslin: You made a strategic decision to stop doing disability research because of the funding problems and because you founded BPA. Is that the right--

Collignon: We stopped going after the training grants because of the stupidity of how the Feds were administering cyclic problems. We stopped doing the research grants because I thought it would be a conflict with BPA. I didn't want someone to say, "Oh, you're starting stuff on the cheap in the university and then making profits in BPA." So we tried to stop just so I wouldn't have any conflict of interest.

Research Studies: Independent Living Policy Issues, Education, Employment, and Race

Breslin: Tell me a little bit about the early research work that you were doing with BPA that's disability related. I know you have an enormously long record of research in the field, but are there any particular pieces of work that you did in the early stages that you think contributed to the advancement of the disability cause?

Collignon: I can think of one that had a large impact in D.C. Whether it did broadly in the movement, I'm not sure. Congress had mandated that RSA do a study on what the aspects are of thinking about the 1973 Rehab Act after they had passed it. Urban Institute had a lead. We did a large subcontract with the Urban Institute at one point, and one of the volumes was on all the aspects that would contribute to independent living. We tried in one volume to sort of look at policy issues, housing, transportation, et cetera. And it actually got a very wide circulation in Washington at that time because there was no other comprehensive short volume. The Urban Institute came up with a report that was 2,000 pages long. This was containable in eighty pages; some sections were better than others. A few sections actually got put in the same volume.

We did some analytic pieces that impressed different government agencies as we tried to evaluate VR performance. Some of them became the basis of ongoing methodology that

people used. I remember one of the earliest findings were that investments in education actually had a strong positive benefit-cost payoff. I don't know if I said that right. Everyone used to say it's so expensive. The point is, the moment you did any follow-up of clients, it turned out that if you spent more money in education helping people learn how to make use of the skills they had and getting human capital, they held the jobs longer, they got much higher pay, and thus in fact it was a bigger payoff for what nonetheless was an original outlay of more money for education than there was in the training programs. Every time we've ever been able to do a study that had follow-up data, that's come through. Of course that goes totally the opposite direction of what VR directors want to do, which is usually to discourage that kind of high-cost investment as opposed to low-cost investment.

Breslin: When you say education, you're talking about postsecondary primarily or other kinds of vocational training?

Collignon: Both postsecondary and more extended job training. But actually I think we really argued that--postsecondary was the original one that came through. You have all these people with a disability with a great deal of talent, but their dilemma was their inability to gain the access to the education and often that piece of paper that was going to mean a much higher pay rate.

Another study that I think had importance in D.C. debates was--and the movement though was less likely to find this one happy. The studies were fairly clear that disability was less a barrier to employment and higher earnings than were things like race. We tried to identify very early that minorities who had suffered major discrimination were a particular problem within disability, because that seemed to be much more significant a factor than a severe disability. An individual with a minority status who had a disability that was normally not seen as that much of an impairment was given a much harder time getting in the job market than an individual who was white and had what was generally seen as a very severe impairment. We did a number of state studies later on that pointed out--and again it just kept consistently coming up in the data, and it was suggested you needed to make major efforts if you were going to be able to deal with minority disability groups. That severity of disability was very important, so we paid attention, but there was not nearly the employment handicap that some of these other traits seemed to have been.

Breslin: That's really fascinating. I'm sure you're familiar with the 1986 Harris Poll data, because it's what was used for lobbying

purposes for the passage of the ADA. How does your study then jive with the [Lou] Harris reports that 70 percent of people with disabilities are unemployed and people with disabilities are poor?

Collignon: Well, number one, the studies we are doing are looking at the people--not at all people with disabilities, but literally the people that the government is trying to achieve employment with.

Breslin: VR clients.

Collignon: Right. They're looking at VR clients. Harris is trying to say, "Here is the whole class. How many people are getting help, and are they succeeding?" We're trying to say, "When the government is trying to help, does it work? And who do you have to put more investment in and what kind of investment do you have to make to have it work?" The answer is ultimately more investment to cover more people. You try with more people, but then you're also trying the right way with more people. That's the goal.

And the other thing that we were putting out there, which I think was important at the time in the analysis, was that it was not interesting in most of the studies to determine that severity of disability led to lower earnings or lower probability of employment. The issue was how do you get people with severe disabilities employed? And the focusing of the shift as a result of the '73 act is what we were arguing at the time, to focus on what worked with people that had severe disabilities, not the fact of simply repeating the fact that severity of disability was hurting your prospects. That was a fundamental intellectual shift that we did. It took a long time. I think from the very beginning they represented some major intellectual directions. Part of our argument, which I can't say was born from the quantitative research but more from the observation, was that you were more likely to succeed if you complemented the employment with independent living services. That was our pitch.

We were usually in thirty or more states each year, working with states, and that was a very consistent pitch. You can't show them the data, because the data collects nothing on independent living. But our belief was that if you could make it easier for that person to get peer counseling so that illness didn't arise from their inability to know how to cope with different things, and if you could provide them backup transportation, et cetera, then that person was going to hold the job. Those were often seen as services that VR did not

provide or was caring about, and we believe that if only they were measured, a high predictor of who would be able to continue to hold the job over time and maybe who first got the job.

There, to this day, has not been the kind of study that provides the combined data on the employment services and the independent living services with a large enough sample that allows you to test that. We could never get a federal agency that was willing to change their data system so you could create it. And later on when we did independent living evaluations, we discovered that the independent living service agencies were not really willing to create databases; it's very hard for a CIL to create an information system with every client, you know. That's asking them to be like bureaucrats and the feds. It requires a different kind of study to do that.

Breslin: When you were doing these studies--actually, tell me the time frame here if you can remember. This was mid to late seventies, primarily?

Collignon: The firm got launched in December '72. So the first study, let's say '73, '74, '75--I'm talking about the kicking off of the firm--there were a couple state studies we did--one of my favorite memories, I--Joan and I basically took camping trips for our vacation, because they were cheap, but we had the firm now, so the first summer after the firm I said, "Okay, I'm going to take a day off in Olympia." I went into the state agency--I had carried a coat and tie on this camping trip just for that moment--walked in and walked out with a \$30,000 contract to do three studies for the state legislature that I later had to testify at.

But two were analytic studies--one of them tried to ask, "Does combining super-agencies create greater effectiveness for a VR agency than allowing it to be a separate agency?" We actually documented that no, separate agencies had more effectiveness than when you combine them. This meant keeping VR, which really meant keeping a main focus on disability, rather than trying to simply be a comprehensive service for all types of people with social attributes that were seen as creating problems for them. That study actually helped get us a lot of visibility with CSAVR: one, it said something that CSAVR wanted to say--that's not why we said it. We said it because that's what the data clearly showed in analysis of fifty states. Some states had combined agencies and some had separate, et cetera.

Breslin: I was asking about the dates that your employment studies encompassed, because the period of time that you conducted the studies where you drew your race conclusions--

Collignon: As I said, those studies weren't consistent over time. The first set of data would have--I don't remember now--but it would have been pre-Rehab Act.

Breslin: Pre-'73.

Collignon: The study was done between '73 and '75. It probably had to deal with pre-Rehab Act. We later did a major study for the audit agency and the Office of the Assistant Secretary at HEW that looked at '75 data, and more recently we had a study that was late-eighties data, and probably one or two in between.

Breslin: In the mid-seventies period, where you had a number of projects ongoing, did you have occasion to look at issues applying your social construct theory to the outcome of employment in VR? For example, was prejudice considered in outcomes? It was certainly considered in race--it was a factor in race. Was it a factor in disability?

Collignon: The answer is yes, it was, but not in a consistent fashion, depending on which type of disability you were talking about. Obviously none of the databases permits a look at prejudice; it's hard to judge that federal governments routinely generate --and if you ask an individual, they will say, "Oh, I'm confronting prejudice." And we did a number of studies that suggested that was the case. We had no study that directly would allow us to test prejudice. I can tell you that people with disability felt they had prejudice. The one study that came closest, though it's much later in time--in fact, it's probably like an '86 or '87 study, so it's maybe irrelevant--we actually did a survey of employers in Marin County. It was one of the Buck Trust projects. We were basically trying to understand their reaction to different types of disabilities. It was very clear that far and away the disability that scared them and which they most reluctant to hire were those with mental illness histories, as compared to other kinds.

Breslin: This was '86.

Collignon: Yes, '86. It appeared by then that there had been a fair amount of acceptance. When we actually did qualitative work with employers, I would say early on we discovered that there was a sympathy effect that was very strong--a kind of a "I ought to hire the deserving poor" kind of belief, certainly with most disabilities. There was an awkwardness in being able

to talk about it and being in front of a person with a disability with this huge sympathy that was there. Would they not hire because of it? They were persuaded by this data that was constantly being beamed to them from the feds and from some disability movements--"the disabled person will be less likely to turn over, will be there every day, because boy, they value this job: you gave them the one real chance." [laughter]

Breslin: Yes, the DuPont study is alive and well probably.

Collignon: And before that there was a big federal study in 1948 which the feds funded. I later dug it out from the library. It turns out nobody had read it in twenty years. Methodologically, it had some fundamental weaknesses which I don't like to talk about too much, because it really had misrepresented some of the conclusions.

Anyway, it was clear, I would say, from the qualitative as well, that mental illness was very scary, the inability to communicate was very scary to people, and I would say led to potential barriers of discrimination and prejudice. It was different than usual prejudice; it was more of a "I'm so sympathetic, but I don't know how to be around them." That was the way that often it would be confronting people. Well, the issue was you could persuade them how to be around them and to make the accommodation that would work. We later did the major series of studies for Department of Labor on accommodation, which was cited on the floor of the Hill.

Transition from a Charity Model to a Sociopolitical Model

Breslin: I want to talk about that in a little while, because that's an important piece of ADA's work in the field.

This period though in the mid to late seventies is of interest to me because--and I think very much of interest historically, because the disability movement as written by a number of people perceives this as a period of transition from sort of a charity model of disability policy to a sociopolitical model. Your work and your contribution in terms of research had to have been looking at some of these factors, if not absolutely directly, as a part of the overall picture. The questions that I'm asking you have to do with helping us understand what that contribution was in terms of your research. You've answered it to a large extent, but if you have any recollections or observations--

Collignon: What I probably ought to have is the list of published research pieces that spring things to mind. The key you have to recognize is that BPA was never, in my role, just about research. It was also how do you do the consulting that makes the social change? So the point is that the advocacy--we're trying to write new standards for how you evaluate federal agencies, but bring into those standards retaining people in employment and opening up on independent living. So we're trying to push on the state agencies to open up to independent living services as something they ought to be supporting, and that will be complementary, and they ought to put some of their own state money into it.

We did the first study for California, all their independent living studies. We did studies for a number of other states on that. So it's research, it's not the big national impact stuff. The research for the state was as much to help them understand what an independent living center could be, what some of the alternative models were, that really the issue of independent living centers that state agency professionals didn't run but which were run by the people with disabilities themselves was okay. They would be well-run, they wouldn't waste taxpayer money, and they could provide a special service that would probably make people more successful as the state viewed success. This was also part of what's happening, because again it was a planning organization; it was not uniquely a research institute. So that's part of the selling job at the state level to assure them that as they're getting political pressure from down below, that they're not going to be necessarily confronting scandals when they later do audits of how the money's being spent. I think it's not a trivial factor.

And we were in so many states during that period. I mean, it's probably true that we have been in all states at some point in the history of BPA. In the early years we were probably in fifteen, but then we got up to thirty states a year where we were working under some aegis one way or the other.

Ed Roberts' Impact on the Independent Living Movement

Breslin: I want to digress for just a minute and ask you to think about Ed Roberts and his relationship to the state VR in California, because this was certainly a period when he was having a major role and impact. Do you have observations about Ed's role with respect to VR? Do you have recollections? Do you have

thoughts about that period? You were in the midst of evaluating and having personal relationships with people involved in the movement.

Collignon: Ed's impact was dramatic in California on legitimating the movement, saying there was new social policy that was going to be the way for people with disability, and getting huge public visibility for a changed concept of what services ought to be like. I rarely could go into that office, of local VR--or even of the old-line professionals in the state--without hearing Ed trounced and denounced and what have you by the professionals: "Didn't know how to run an agency, didn't know how to blah blah, didn't even understand VR, a disaster!" A lot of that was because politically he came from such a different direction than they were used to. It is probably true that administratively, folks around him were not as experienced and professional as the folks who routinely were brought in. They were there for a different purpose under Jerry Brown. I don't think they did harm; I think they did major social policy change, and that was good. It's probably true now that one would also--

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Breslin: Fred, continue on with your thoughts about Ed Roberts, if you would.

Collignon: His being at the top also meant that a number of other individuals got the experience of being in that kind of role, thinking really big about how you transform a state agency and think about new policies, and also got them résumés so it helped them in their later careers. John Hessler, Joan Leon--a lot of folks really got some major opportunities and they were also very useful to Ed in all kinds of ways too.

But I think how much change Ed was actually able to do on the infrastructure of California rehab was less than he wanted or hoped, precisely because it is a state-run program but with all federal money for the most part. It's a state match. And federal rules guide that program much more than state policy does. So things that Ed might want to change, he discovered were in the regs that the feds had issued. I think they didn't understand that you can't just walk in and say there are right and better things to do and they'll happen. As I said, it is a political system, and those regs are there because they protect a lot of interests--in part, professional definitions of disability and what people need. They have to be transformed, those regs, at the federal level, not at the state level.

What you can do at the state level is launch some new programs. So what Ed did was get the funding for more centers for independent living besides the couple that existed and made it a statewide program in that period. He could do that, and Jerry Brown could say let's do that at that period. He could begin trying to, by putting out some different images of--gee, a person with a disability has a right to make more of these decisions themselves--and I want them to have a major impact, to begin changing the way some professional counselors actually dealt with them. He could begin changing who was hired by saying, "Rather than simply hire the folks with psychotherapeutic blah blah, let's do folks with a sense of how you cope and find housing and transportation and so on. That's the skills that I want the schools to be preparing people in that I'm going to hire from, and they're the kind of people I'm going to hire." They can make those changes which are different, but it's hard to change those schools too.

It takes a couple of years of pressure, and I don't think it was long enough to do that. But I think those changes he started making--people who were seen as rads, far out among the VR counselors in that period got to be managers of offices. They weren't so far off that they didn't understand how to be professional. But they had the kind of value system and the images of rehab that were more consistent with where Ed wanted to go. They had their whole career line shifted, so they got to be in charge a while. How long they stayed, et cetera, I can't tell you because I wasn't necessarily trying to monitor that. But I think those were the impacts rather than the ability to transform the mainline VR system. I think the mainline system thought it was at war with Ed the whole time and probably felt, from its perspective, that it won. It outlasted him. Which is what bureaucratic organizations always do with reformers. They figure "I'll be here longer than you. I've got civil service. You'll come and go eventually."

Breslin: There's some truth in it.

Collignon: There's great truth.

Evaluating the Effectiveness of Title VII Programs on Independent Living

Breslin: Let's revisit BPA just a little bit. You did an enormous amount of work with BPA with regard to the Title VII provisions

of the Rehab Act, establishing the centers for independent living nationally. You did a research study in '86, I think.

Collignon: Yes, it came out in '86, so it probably started in '82 or so.

Breslin: Evaluating the effectiveness of the Title VII programs.

Collignon: Right.

Breslin: Can you talk a little bit about your approach to that study and your conclusions and what impact you think it might have had on independent living in general, if any?

Collignon: The impact, fundamentally, a lot of the standards that later came out of those big battles with RSA were taken directly from those standards. That's because the independent living movement found those standards for the most part compatible. They [independent living centers] were going to have to have standards; once they accepted that, then they agreed that they would help work with us in shaping standards that both made sense for the feds and for the movement, and thus they [those standards originally suggested by BPA] became their standards. Eventually they were the ones that were adopted. They never adopted them as BPA standards. They always have to get renamed, and that's fine. At one point CSAVR adopted BPA standards directly and they said, "These are the CSAVR rather than the BPA standards." [in a pompous voice]. We said that's fine. That works.

Something similar happened to independent living, although we were still in pretty good shape. Generally what we found is the feds usually wanted routine quantitative standards with a heavy emphasis still on rehab and people graduating and getting out of the program, et cetera. Originally the centers were not anxious to have measurement at all because of the cost of counting bodies, et cetera, and all that information systems and bureaucracy that were implied, and all kinds of other control over them that's implied by having standards, that you weren't an ongoing support base for people. But we tried to create standards that allowed more of their concerns to come in while understanding what we believe the feds needed. So we were the broker between the two. We could be the broker because we already developed standards for the rehab program, we developed standards for a couple of child abuse and neglect programs nationally, we were doing things that were akin to standards for a few other public agencies. We had a lot of history at this point of having helped agencies accept standards that ultimately came into play.

We kind of were the brokers. I was not the key broker person here at all; it was really Linda Toms Barker, and early on Sue Stoddard. Really Linda was the monitor of this project in making it happen. She spent a lot of her time trying to be this broker. It was very difficult; the feds would get furious at her because she wasn't following their direction. And my role was often trying to, "Okay, Linda, we have to figure out how to do both," and try to heal it while protecting what she had done with the independent living centers. But it was an interesting kind of tightrope between the two.

The feds were used to consultants who simply did what the feds wanted and getting their way. And that meant planning through the bureaucratic. Our judgment always meant we're independent. Several times in our history RSA has said "We're no longer hiring you. You guys did something we didn't--not the quality, but took a position--." Sometimes CSAVR said, "You guys, we're going to blackball you." And our statement is, "You'll come back to us," because the issue what we have is our integrity. We do high quality work, the integrity is there, we call it as we see it, and that has value eventually with Congress or with other constituencies. And BPA, at least in my period, survived three or four of those would-be blackball periods.

It was a really tough project, and Linda did a brilliant job of managing this. And Sue was a key partner in really helping launch the study with Linda. Sue went off to form what became Info-Use; I can't remember whether it directly became Info-Use or a little later. Maybe in the first year of the project. She certainly helped give it a good start and had been very key in working with a lot of the state programs over the years. Sue really did that original evaluation of California independent living centers for us and was very much a part of making these evaluations and standards happen.

Breslin: You conducted two other studies, one involving the cost of accommodation in employment, and a second study involving effectiveness of the ADA--I think in '95? Or was it a draft?

Collignon: I can describe that [inaudible].

Breslin: Okay. Both of those studies, I think, are really relevant to BPA's role in disability policy. Can you just talk about those a little bit from your personal perspective?

Collignon: Sure. The accommodation study really began as--[Department of] Labor wanted to do a large study which would repeat that 1948 study; and document, they hoped, that people with disability

had these wonderful advantages. People really knew they had to do a straight research study to do that. The contract they launched was to include that and was also to include aspects of when employers do accommodations. How much does it cost? Is this creating this major barrier? Because in the Small Business Administration, they were taking the stance inside the administration, based on their constituencies, that "this thing is outrageously expensive. It's causing small businesses to go broke and costing the taxpayer tons of money and what have you."

We went into the study to do both, it being very clear to the Department of Labor that we couldn't guarantee that if we did a good research study that we would necessarily have the same results as the 1948 study. You could say we hoped we would, but research would fall where it would. It turned out they had politics that basically said--and maybe it was dealing with other constituencies of those with disability in Washington, formal organizations--"Wait a minute. We'd rather you not do a study than take the risk that a study would come out that did not say what DuPont and the earlier '48 study did." That was fine; it was their call. We certainly didn't want to be in a position--but the issue was if that's what it said, we would, you know--. But one thing we are is that we were an organization that on the research side did first-rate research but called it the way the research came out as opposed to the way we wanted the politics to come out.

So that component was dropped, and the study became principally on the actual experience with accommodations. Now these were the accommodations that were mandated under the much earlier legislation. We now have a much longer experience. We did a survey of firms nationally. We actually had a far better response rate than most surveys of firms have, although response rates are always problematic. We did detailed case studies on a number of large firms, and we did surveys of people with disability in those firms, quite apart from the survey of workers. We put together a lot of data; it was the only data that existed nationally. And I think it still is the only data that exists nationally, but I can't say as I've done the literature search the last couple of years. I haven't heard of a new study in the area.

What it basically showed--we coined it one day as "Accommodation is no big deal." What we were trying to do was to put a hole in the balloon that said this was this big issue. Now there are limitations; we were very clear. This study focused on the experience of accommodation of those who were already employed. What it doesn't say is if you hire a person

with disability or if you were to hire a person with a severe impairment, that theirs might not impose more. But what happens is, if a person incurs a severe impairment because of an accident, of aging, or of health, these firms fall over backwards to accommodate them.

Breslin: If they're working.

Collignon: If they've already been a worker. And they don't find it to be very expensive. Well, there's not an obvious lot of reasons why the costs should be dramatically greater for a person who has a major severe impairment because of an accident once there than a person trying to get the job. But what is true is that they know that the person already there is socialized to the workplace and has a decent work record. Those types of things are there. But they don't know that about the person outside. So they can be reasonably confident about what they're going to get.

Secondly, they believe that it will be seen as being a good employer by fellow workers. But the reality is most of the time the accommodations didn't cost much. Most of the time when they did cost something it was because the firm never asked the employee what they needed to be able to be adjusted. The big push was "Ask the worker what will accommodate them rather than take some textbook statement." Because you may find that it's a very cheap accommodation that actually satisfies the worker and helps them do what they need to do rather than a very big expensive one. There was this big finding based on lots and lots of firms. Well, are there exceptions? Of course. If you have to put elevators in your building, that's dramatic. But that's not being based on a combination of workers; that's now more standard federal law under ADA. It's a very different issue than you need accommodation. So you have to lower the height of your water fountains; it's not that expensive. So anyway, it was based on a very large sample.

We then dealt with individuals who had disabilities, and they reported observations very similarly: these accommodations weren't very expensive. There were some issues that were left standing: the cost of hiring brand-new workers, and then secondly, what is needed to help that person with a disability advance so that they can get promoted over time? We didn't fully study that, but there was some indication that that was something we should look at as to what that experience is, because it's different than what you're able to sustain or keep your job or remain productive. Well, it turned out to be the only study one could find with any real data that was of any

size, so it was cited on the floor during the ADA debate. Congress relied on that study, because there was no other data. If you were trying to scare folks away from ADA by the costs, it was the one thing they could come back on. As I said, ADA goes much further than that, because it deals with accessibility generally to buildings and elevators and so on. That's a different issue, and there is more cost to that. But I don't believe the accommodation issue per se was the big cost factor, and I think the study may have helped persuade a number of even Republican congressmen that they could live with the cost. After all, it was a Republican president who was willing to live with this bill.

Breslin: That study was, as I'm sure you know, cited rote by memory by every advocate involved in working on passage of the ADA. It may have become somewhat prostituted as it was recited. [laughter] It was a very, very important piece of information. It was the single, and as you said, the only piece of information available that really went to the question of cost and accommodation. It was a very big contribution from an advocacy perspective.

Collignon: The other two principals with me on that were Mary Vincel and Linda Toms Barker. They were the two principals for doing that. It was one of our major ones.

BPA, after I retired from it, seems to have gone more in the direction of labor studies more recently, so it does a great deal of literacy in the workplace and employment studies generally and evaluation, et cetera, as much as they do disability. In some respect that experience with Labor was the beginning of the labor relationship as opposed to uniquely disability.

There were a couple of other studies that you might have seen from the advocacy movement that I think were important to disability policy, that I would throw into the hopper here. One, that audit of the '73 Act was very important, I think, in showing where the agency had not implemented yet and where it could. We did this study the first time for HEW, jointly sponsored by the audit agency of HEW and by the Office of the Secretary. But among other things, it tried to assess how much change the '73 Act had done, but highlighted where changes hadn't occurred. It called internally for pressing among agencies to push in directions. It continued to do major evaluation of what worked and didn't work with disability populations, which I think was fairly important.

It came closer than a lot of studies to bringing in some of the aspects of independent living, because we had auditors interviewing people with disability. It never happened before; I don't think it's ever happened since. But they were able to ask the people who had been clients of VR some of the questions about things that related to the rest of their life. It introduced some of the aspects of independent living to VR. There's a national study currently going on--I haven't seen any reports out yet; I think North Carolina's doing it, and Sue Stoddard may be advising them--mega-evaluation, and maybe that study is now going to bring the agency data together with client interview data. But that was one of the first studies that did it, and I think it helped push--the '73 Rehab Act wasn't just on paper. You had to think about what it took in the everyday life of a VR client to implement it, and it was a key pusher.

The second, and very different, study was we did the first evaluation of the proprietary rehab sector. The private, profit rehab sector. Not all profit; some of it was nonprofit. And in that we did a fascinating sub-study, I thought, besides surveying all the proprietary industry, we had an internal experimental design study where in Michigan we had a case where the state agency was allowed to compete with the proprietary sector in serving the proprietary sector's normal clients. The state workers' comp client.

Workers' comp clients, by definition, already had jobs before they got injured, so are more likely to be able to be returned to work. So they're serving, if you will, higher-prospect clients. Proprietary sector versus VR. But here's the public agency moving into the private sector's turf. In Arizona we had the opposite: we had this Arizona state VR agency, but we had the proprietary sector dealing with VR clients. What we found in the cases was that the proprietary sector loved the Arizona findings, because we found the proprietary sector in Arizona was as good or better than the state VR, but in Michigan we found that the state VR was better than or at least as good with clients as the proprietary sector, to which the key aspect was competition.

It seems to be what may drive part of this--that if you're allowed to compete or have to compete, you tend to work harder and get better. So each agency--public VR could see a future in "some privatizing" just as the private sector could. But one of the reasons that was very exciting to me is it opens the door to saying the key is competition, and so can independent living centers become major providers of the VR service in a competitive mode. Going back to that voucher

discussion, well, this was dealing with public proprietary. I found the results, and the results were what the data gave; it wasn't what I--. But they were very consistent with opening the door to a privatizing, but in my mind, public sector privatizing is really going to mean not as often private profit, but nonprofits being able to compete.

I believe that the movement is now starting, and over twenty years will continue, to offer more and more of these services in competition with public agencies. The issue is getting professionals to let go and being forced to compete with the nonprofits in delivering the service, and someone evaluating the effect and whether it does what people want. I view that study as immensely important, and it is the first study that the proprietary sector had ever done. The proprietary sector printed huge numbers of copies, but as you said the use of it, they like to cite the Arizona ones. They don't like to cite the Michigan findings [laughter].

Breslin: I would love to actually talk to you sometime about your views of economic development opportunities for nonprofits--particularly disability-related nonprofits like CIL, which is a little separate--but I'm really interested in that subject.

Health Insurance Studies: Supporting the Americans with Disabilities Act

[Interview 3: September 17, 1997] ##

Breslin: We're going to talk about some of the work that you did studying the effectiveness of health insurance and the impact it has on disabilities in the late eighties.

Collignon: Okay. There was a series that we did. The first was part of the reasonable accommodation study, but it involved trying to understand the extent to which insurers were prepared to finance rehab. It also involved looking at private firms that hired either rehab consultants directly or used their insurers, and then finally looked at the various kind of private vendors who provided rehabilitation services to private insurance and such firms.

The key to that was that these firms literally were not part of the public sector at all; they were uniquely part of the private sector that had emerged to respond to the insurance claims of individuals. I think I noted on an earlier tape that

another study actually compared the effectiveness of the private and the public in terms of privatization, so we won't go through that again. But a key thing that emerged was that the private insurers don't really do rehab because it saves them money; they do it because it sounds nice, it looks nice. Their money is not based on whether people go back to work or not. Their money is based on getting the premiums and investing them and getting a good return.

While the reformers within the insurance movement believed they ought to be thinking about how to save themselves some money by doing rehab, the reality was that for most of the insurance firms this was a minor consideration. The goal was to get the premium, to invest it, and they were perfectly willing to fund indefinitely many individuals to sort of stay off work or what have you, because that wasn't how they viewed their industry and market. So we were quite shocked, you understand, that within the health industry the reformers were having a hard time persuading the health industry to simply look at what was the obvious economic return they could have.

Later we did some additional studies--well, we did some studies for states to determine whether they could create greater incentives for the private insurers via workers' comp to get into workers' comp rehabilitation. Some states dealt with the political battle to try and peel back the rehab gains that had been made. Insurers simply didn't want to be required to do rehab at all. We often ended up providing the ammunition used by the states to the legislatures for maintaining some of the rehab requirements.

So we did another set of studies on insurance as it affected provision of medical services to infants and youth who had chronic disabilities. Those studies showed that the young child who had a disability and who was from a family that was already on welfare, by its access to Medicaid, actually had pretty good coverage, that there was pretty good coverage under the insurance plans for many of the disabilities that a child or an infant might have, for the working population.

The biggest problem was the working poor. Those folks who were on the margin of employment, who either had no insurance through their employer, they were the ones left out. Basically what that says is the experience of disability is not different in kind than the experience with health care services generally.

There was a second problem, though, that emerged, and that is that although the plans covered services fairly well,

it was shocking how many families--even well-off families--would not take advantage of the medical and rehabilitation services that were there for the children. If they had to pay even five or ten dollars, they wouldn't come in. First we thought, therefore, that maybe it was the economic disincentive of paying even that small amount of money. But a lot of these are fairly affluent families, so it didn't seem that that would explain it.

It was denial that their child had a disability that they were going to have to overcome with whatever sense of stigma they thought it meant for the family. It was the sense of not wanting to get their child labeled, and certainly not labeled with a developmental disability and all that that might mean in terms of how the child had to experience the school system.

But it was quite bizarre the number of families that weren't making use of medical services that were available. This had long-running implications for the child, for the society. Because society was going to have to spend a lot more money later on in health care and in educational services to make up the deficits for which the family was not seeking help. We tried to suggest that this was really a serious problem we were going to have to work at.

Yet another study, we actually reviewed the HMO's [health maintenance organizations] that were available in California and tried to judge how good they were--

Breslin: What year was this?

Collignon: This is probably '89. How good they were in covering child services and adult services. This is intriguing, because we had done a comparable study back in the early seventies, and that study--by Lauren Leroy, if I remember--had shown that most of the programs had nothing on rehabilitation back in the early seventies. Well, by the late eighties they had a fair amount on rehabilitation. There really had been a major change in the routine services that were being available via HMO's. But they varied widely: how many trips to a shrink could you really get? So the mental health care was clearly less well-funded and provided for than physical rehabilitation care.

We evaluated all the programs. The interesting thing is the HMO that clearly emerged as the best in service that was offered under the plan was Kaiser. It was far and away the most outstanding.

Breslin: What other HMO's were competitive in this time period?

Collignon: I'd have to go back and look at the study. We looked at over fifty-some HMO groups.

Breslin: In California?

Collignon: In California alone. Don't forget that by then you already had the requirement that most employers I think had to offer an HMO option to a private insurance option. I think by '89 that was routine. There were a lot that were available. But Kaiser was just head and shoulders above all of them. And that was intriguing because even some of our own staff had used Kaiser and had had their battles with Kaiser as they tried to expand coverage that was available to them. In this period, BPA clearly had two-thirds of the staff working on disability issues who were individuals with disabilities themselves. So the firm had a lot of experience trying to be the broker to expand Kaiser's provisions. But the staff fairly did the analysis and were quite pleased at what emerged. So anyway, it was very clear that this was a whole area that needed study.

What was in the literature was much more narrow, about who's abusing the workers' comp system and the waste of spending money on rehab, and the institutional practices whereby firms would put a person on permanent disability as their way of getting the person out of work. Whether or not they had a disability was the issue. A person gets furloughed basically with a nice compensation, the union now feels that person's now well taken care of. The firm's got them out of employment, and meanwhile the person's put permanently into a disability loop, which doesn't help those with more serious needs.

At the same time, we did some studies here at Cal that talked about the number of cases that were coming into rehab that were potentially cases that should have been in the workers' comp system years before with employers. But the individual at the time didn't recognize the disability as one potentially related to the occupation or the work that they had done; so many of their claims on workers' comp had expired--or worse, they had some valid claims for an injury that they had pressed, but workers' comp basically works by settlement, as you well know, and they had signed off. They had gotten some money up front, which they thought was going to tide them over, and of course it tided them over for a year or two. Meanwhile, they're then poor, they're without any sort of training options, what have you, and they're coming into the public system, which is assuming responsibility for something the private employer insurance system ought to have done.

Now we tried to raise this issue to the public rehab sector. It was hard to do because the data was fairly limited, but we did a couple of studies with some individual interviewing and similar sorts of things to try and say, "This was something public rehab ought to look at," because it also might save itself some money and do better early intervention if there was more association, continuity, and integration of thinking about disability with the workers' comp sector. To this day, we do not have a good handle on the number of disabilities that may have an occupational source, in my judgment.

Breslin: I think that's right. Did you look at the prevalence of discrimination against people with disabilities by health insurers in any of these studies? Do you remember?

Collignon: We didn't have the data--I mean, we had anecdotal data: when we interviewed people we'd get reports. There was no data to look at that. But surely we had looked at studies of discrimination in employment data, generally, but not linked to health insurers. I think I may have told you on the earlier tape that we had an econ dissertation that was modeling discrimination--did I already use that story?

Breslin: Yes.

Collignon: Okay, so I won't do it again.

Breslin: This period of time, of course, just precedes the enactment of the ADA. One of the big contentious issues in the early drafts of the ADA was the application of nondiscrimination provisions to health insurers. I'm wondering if you recall a linkage between work that you were doing and this very contentious early proposal to cover private insurers under the ADA.

Collignon: I think the linkage would have occurred via Department of Labor staff who were using our data--we weren't being directly involved in that kind of debate. The folks at Labor who were pressing on it often had disabilities themselves and pretty much found their data the main source that they had that were dealing with the issues that had some sympathy for the consumer side. But I can't claim that we went up there and said, "Oh, here's the piece of legislative stuff you ought to be doing." It's much different than the '73 rehab.

The consumer movement was pretty darn good and organized at that period. It knew how to fight for itself.

Breslin: There were many issues that it knew how to fight for, but the insurance issue was one that really called for studies to substantiate a point of view. I'm sure yours came into play at various points along the way.

Let's move on to your relationship to the ADA. You were involved in a fair number of studies after the enactment of the ADA. Actually, I'm not sure if you were involved in work prior to the ADA that related to it directly. Can you talk a little bit about--

Collignon: Well, the one most directly related was the study of reasonable accommodation itself, that looked at the costs of accommodation based on a national sample survey that we did on employers. I think I talked about that accommodation is "no big deal" as being the phrase. And that was cited on the floor of Congress and cited in the OMB studies, because no one had any data on the cost of accommodation at that point in time.

Breslin: The interesting thing I've learned from you in hearing you talk about that study is that it applied to workers who were employed.

Collignon: Right. Left out those who hadn't gotten the job yet.

Breslin: And that was a detail that was conveniently omitted when that data was being used to argue for the ADA.

Collignon: Definitely, it was conveniently omitted by the advocate agencies in the feds as well as by the consumer groups.

Breslin: And we thank you for it [laughs].

Collignon: I admit: when called, we would occasionally make sure that we had said it somewhere, but in a way that people were not necessarily doing their major focus on it. Subsequently, we did a lot of work with regard to Department of Labor studies, transition to work, literacy--but disability would arise in the context of special learning problems and other things that people would encounter in the extent to which schools and employers would cope with those. It was less of a disability policy focus than how Labor can implement some of those programs.

We did do a fair amount of work on supported employment, which was one of the responses to problems both prior but particularly after ADA--we wrote the standards--well, we drafted as we convened large numbers of players, both consumer

advocates and employment agencies and rehab agencies to create standards for supported employment programs.

And by supported employment we meant an issue where the employer was providing some special assistance to the individual as they were engaged in their employment. And if we go as far as even a job coach who was there helping to provide the training--one of the things we pointed out was that a problem that both large corporations and particularly small firms have, is that they really don't provide a lot of good, first-line supervision for the new entry worker. They had very low-lying supervisors who don't know how to deal with people that may present any special problems and who were far more likely to have prejudices and other things than probably the more senior manager who has gone through some educational training and similar sorts of things. So often the job coaches and their various related techniques were very important in looking at that entry worker--what problems were they having getting away from any of the prejudice and figuring out how to make them successful in the job that they were doing.

We very early on had adapted some of our techniques from the Massachusetts model that was being done, tried to sell it in the state of California--very early on, even before ADA. California did not start getting very active though until after ADA with regard to these types of programs. There's still a growing proportion of the budget, of the Rehab Services Administration intervention budgets. So that was one major area, which I think was particularly relevant to the entry worker, dealing with the other side of that reasonable accommodation study that we had.

I advised and had some activity with--but really wasn't the majordomo--some studies that were going on by Ed [Edward] Yelin and Mitch [Mitchell] LaPlante and their disability statistics centers, which I think was starting to document what really was happening with employment of people with disability, using a wide array of different statistical bodies of data that the government had already collected but nobody had really looked at to try and probe what was happening in disability. I think they've done some really good stuff.

They tend to shy away from making any policy judgments: "Here are the facts, ma'am; don't ask me what to do about them." And I guess I was the one pushing from the inside to say, "You guys have got to tell a little bit stronger story if you're going to get the public interested." But they were really first-rate in the development of facts and the handling of these statistics series. And I think it was really needed

in the rehab field. They had a little tendency to shoot from the hip and say, "Well, here's a massive problem; it's pretty clear if you had looked at the numbers that we were jumping too quickly into saying there was a problem where there was a success." They weren't really based on what I would call sound analysis; they could be easily torn apart. I think that the center in San Francisco really did some great work in trying to cut through that.

We did a fair amount of work with the Small Business Administration as it tried to think through how small businesses adapt their employment patterns and supervision to disadvantaged workers, broader than just disabled, but did some specific attention to disability. We worked with David Drury and others in particular. We had one report to Congress on the work of the year by the Small Business Administration; I think they studied four studies in particular, and three of them were ours, which made us feel really good that year.

Again, the problem with small businesses, not merely do they not have a lot of highly skilled people assigned to entry-level supervision, but a manager of the small business is often the owner, the person handling the cash registers, the person handling the inventory: it's a one-person enterprise and they have no supervision. What happens as you glance out of the corner of your eyes, they most often wanted people who could perform a wide array of functions rather than specialized functions, which made it very difficult for people with disability to actually mesh in a small business. That was important, because even on the left there was a strong tendency to say, "Small business is our future, where we want to go." We were also saying, as were others, "Wait a minute. Let's recognize small business provides very little fringe benefits like health insurance, et cetera." But the other aspect is they were highly unlikely to be major employers of people with disability.

We did experiment and advise various independent living centers that were starting to get into their own businesses. Could some of these centers create some spinoff businesses that would be owned and managed by people with disability, and ideally disproportionately employ people with disability? In some ways, it was like kind of a successor to the sheltered workshop but without it being quite so sheltered. But all things being the same, I think the analogy was more akin to a sheltered workshop than a true business. They often were after reserve product markets just like sheltered workshops; they often wanted some major employment subsidies to make it work. Often they had a hard time surviving, as far as we could see.

Breslin: Can you give examples of centers that launched those kinds of economic projects?

Collignon: I could if it were all recent in my mind now. That's the dilemma.

Breslin: Were they California centers or [inaudible]?

Collignon: Actually they were all over, as opposed to being uniquely in California. I know for example that CIL has been trying for ages to find some products, but that's not a good example because it never really launched one. I think there was one in Long Beach that had launched a product. And they could be things like "We're cleaning out the offices at night, and we're often doing it with workers with developmental disabilities, usually mental retardation. We'll handle your large reception phone duties from a more centrally located phone office," so that people in chairs could often do it. They were not different in kind and were often being developed simultaneously by groups that were focusing merely on ethnically disadvantaged groups.

Breslin: You seize opportunities where they rise; that's probably what was going on.

Collignon: What's the famed kitchen? "Eden Express" would be probably the most successful example.

Issues of "Habilitation" and "Rehabilitation"

Breslin: Let me ask you on this range of subjects to reflect a minute about the use of the word "rehabilitation" to describe this very broad range of issues and activities and programs. What's your perception of that now from a political perspective or from an academic perspective? Or from the movement perspective?

Collignon: Way back when in the seventies, there was a clear distinction between habilitation and rehabilitation. Both horrible sounding words, right? But habilitation meaning helping a person initially integrate in the community workforce rather than a person coming back. The biggest problem to the disability community are people that are first truly trying to find forms of work in which they can create a living for themselves. They're not returning to work. If you're returning to work it's an easy case. You're already used to

work socialization, you have some skills, how to dress, how to kowtow to a supervisor, how to do all those things. It's the person who has never had that work experience because of disability that made it hard for them to go in and get that first job as a teenager, and are now doing in their mid-twenties things that often other kids have had to deal with in their teens. They often see it as a little degrading--they think they should be older than that to have to kowtow so much.

Anyway, rehabilitation is very misleading. The rehabilitation game is a much easier game than dealing with a person who is entering for the first time. Clearly when someone has had--we did some work with individuals who had major brain injuries, principally from auto accidents. Now that is a rehabilitation, but it's like starting all over again. The person rarely can even begin to do what they once did. But much more often rehabilitation is a much easier achievement to pursue if you're an employment agency. But again, the whole idea of rehabilitation implies they already were living in an integrated fashion in the community. That may not have been something that happened earlier.

Breslin: One other interpretation of rehabilitation comes from its medical use, which is that you have a broken part or parts that need to be repaired much like your house needs to be repaired.

Collignon: A much older argument.

Breslin: In that context the continued use--some suggest that the continued use of the concept of rehabilitation has a pejorative effect.

Collignon: I guess I left the medical definition behind by the late sixties. I do hear what you're saying. I tend to use rehabilitation, as my examples we're using, as meaning integration in the workplace and integration into a community, as opposed to repairing something. The logic, that is, the individual that needs repairing as opposed to the community and finding some adjustment between the two of us, the latter is how I tend to use the phrase. There's no question to bring up medical people, and that's the first thing that comes to mind. And that's certainly a good reason for trying to find some new language, because words can shape how we respond to things. One culture, particularly the medical culture, has ingrained that in those people who play a great deal in the lives of people with disability. New language would perhaps be very helpful. But it's intriguing, because I haven't thought of that older meaning in a couple decades.

Breslin: It's true the word is used in such a wide variety of contexts that it isn't clear to someone new to the field really what the meaning is. It's clear to you, it's certainly clear to me, but it's not clear to someone who's less familiar with the range of issues that it's intended to cover.

Collignon: Another point is if you look at total spending on disability, and the argument has been that spending on integrating people in the community, last I looked, was less than 5 percent--it was more on the order of 3 percent of total federal spending. So much is straight income or is medical support, et cetera, that it might help to have a different word. So it's clear this is not just part of the medical process.

Disability Studies Program at Cal

Breslin: Which actually raises the question of what's been going on here at Cal in the last few years in terms of development of disabilities studies programs. Can you talk a little bit about your involvement in those programs?

Collignon: With WID [World Institute on Disability] really providing the key initiatives here, we successfully got some grants that provide support for pre-doctoral and doctoral students, the goal there being to help provide some of the future faculty and/or research leaders in the disability field, but aimed at people with disability.

That means that you start with the experience of disability as being part of what you want as you're screening people. That's not affirmative action; that simply says that experience might give you major insight into the nature of the problems, and you are trying to develop some leadership. The program is principally lodged in the public health school. Professor Len Duhl and I have been its overseers for ages, as far as where the grants are lodged. Students can come from all over campus, although there is some priority given to students who are going to do a doctoral in health. But we've had people come from poli sci and public policy and now planning and sociology and moving in these kinds of areas as well.

We, also, with the postdocs have been able to bring to campus some outstanding kinds of leaders that are of use, I think, both to the Berkeley Center for Disability organizations to the extent I view this as a national center and to sort of challenge us, to spread ideas across the different research

centers across the country. We had Harlan Hahn here from the University of Southern California, who I still view as--of all the academics who have a disability--the most prominent in terms of research, and he doesn't have to say he has a disability: he's first-rate in his own sphere without any question. We had people like Jim Mullin, a different level, came out of the state rehab agencies. He came here, and I think he was from Mississippi--that was the state agency he was working with. Again, these people come, they study, they work with WID while they're doing the studies--it's required as part of the fellowship. They write, and usually they're going around nationally sometimes. The conference participation is set up by WID; they put them on the agendas of the various professional and other associations.

We have gotten refunded, so it'll go on for a few more years. We're excited. We're hoping in the longer run we'll be able to end up producing ten or more doctorates that actually could provide some leadership over the next twenty or thirty years in the disability field, as well as do more linkage across the schools.

Breslin: Do you think there's a possibility that the program would actually be adopted over the long term by the university, rather than relying on, I believe, NIDRR funding?

Collignon: It's NIDRR-funded. Programs often still, for their fellowship support, end up having to rely on some funding source, because Cal rarely grants fellowships directly. The other part of this is that we were still hoping to create a disabilities studies program, whether a program within one unit or more ideally in an interdisciplinary studies program that cut could across a wide array of departments at the campus.

We have a graduate course offering and we have an undergraduate course offering. This year we're making the undergraduate course offering one that could work for both undergrad and graduates, so there are two course levels. We've made presentations to the Vice Chancellor for Undergraduate Affairs, Genaro Padilla, about trying to provide us some support to keep experimenting with this. We will hopefully provide a larger proposal to the university in the next year or two.

It's extremely difficult to get new programs running on an interdisciplinary track; it requires major commitment by a lot of faculty. And the reality of Cal is that a lot of faculty have some interest but don't really devote a large proportion of their career to disability. That may make it

tough to get an interdisciplinary program, because there are not enough names that are going to say, "Okay, I'm going to do this for five years." It would probably be easier for it to be a program mounted within a department, like the School of Public Health, and then have other faculty still around the campus who are sending students, who are lecturing in the programs. I think the latter is more likely to be what we pursue. We have some friends in the public health school: Len Duhl, Jean Morton, the dean, the associate dean there. We hope that they will see this as a major opportunity for them.

We also decided the public health route makes sense because that degree, by its nature, is probably an easier degree for individuals with disability to go out and find their academic jobs. We don't want to force anyone uniquely, though, through the door, but it's probably the case that it's easier for them to find jobs in public health or social welfare than some of these other programs. We've had some advising from WID that yes, they can see its logic.

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Breslin: Fred, we were talking about the possibility of the future of the disability studies idea here at Cal. I'm interested in hearing from you what your personal role is in the program. I know you've been a general advisor and you're really facilitating many of these meetings and conversations, but what is your personal role in relation to students and the program itself?

Collignon: My door is open to anyone who comes in to talk, that's for sure. I have reviewed the course outlines for each of the courses being offered. The undergraduate course was actually offered in city planning, so I was the one who could be hung if anything went wrong from the viewpoint of the department. It is now just this year being transferred to public health. Again, it's part of the strategy we described. Talking to individual students, there are probably about seven or eight students from the courses who will come in in any given year. My department often thinks we don't take planning students, and I'd like to point out that we had three who took the course last year, and they were very highly respected students, so that was intriguing to my department.

I go do battle with the provost--"battle" is the wrong phrase. I go and help advocate [chuckles] to the provost as to why this needs money and support. I give it more time than many of the other faculty do, and that helps them have a university-wide imagery as they go to argue why the university

ought to provide support for this. What we most need to make it work is a department that says, "I want to gain primary leverage over all the monies in disability"--really that dramatic--"Let's appoint some scholar who's primary focus is on disability." I have some suspicions that the way it will first happen is for Berkeley to grab a very prominent person first so the person already has the stature--

Breslin: For example?

Collignon: Someone with the stature of Harlan Hahn or someone like that. That's more of a way in which Cal has done these things in the past than take a bet on a young faculty member and see if they can make tenure and the rest. Usually you need some mentoring if you're going to get tenure in this place, and protection in the departmental political battles. Bringing someone who already has major senior status, I think, would make it easier for the overall disability studies program to work. It's moving, and I expect over the next two years a major proposal to go in, and the question is: can we persuade some of the deans and the departments that this is the direction that their faculty ought to hit? I'm hopeful; let's put it this way. I can't say it's more than a fifty-fifty, but ten years ago, as I think I said on an earlier tape, I had one dean who turned down lots of money even though I said, "Bring in a faculty member and I'll turn this stuff over to you." They were just disinterested.

Breslin: That actually leads me to the next question that I want to ask you to reflect on. The presence of a disability studies course or courses on this campus and on some seventy to eighty other campuses around the country some think represent the serious movement of disability rights and disability history issues into the academic mainstream. That may or may not be true, but from your perspective where do you think the disability movement is going, given the fact that campuses and the academic institutions are recognizing the legitimacy of this area of study? What does that tell you about the future of the movement?

Collignon: Clearly we are about to be mainstreamed in the same way as women's studies are mainstreamed. I'm hoping that it's not ethnic studies, where we're pushed to the side. That's the big difference of wanting it in a mainline department, I think, because it doesn't permit that. There is first-rate intellectual writing about disability from sociological, psychological, economic--a wide array of areas--that simply did not exist in the literature when I started twenty-five years ago. That should bring it to more people's attention. The key

is, Can you get disability themes in a wide array of courses and not just disability studies? Disability studies will provide an avenue for disability to be more permanently represented in academic faculties. I think it's very important, because I think I mentioned earlier that the campus frequently frowned on my own involvement in disability-type research.

We did another grant which we had proposed--and I'm trying to think of the wonderful woman who did it; her doctorate was from Harvard--creating disability case studies that could be used in business administration courses and public policy courses and the rest, just so as they did mainline courses, some of their cases, just as they might have something on poverty or transportation or housing was on disability. I also believe that's something one also needs to do. So these other departments can't say "Go over to that study area if you want to do something on that." And I'm hoping we don't lose sight of that. Those kinds of cases are out there, they're in the Harvard Case Series now. I think that's emphatically part of it.

Okay, one, we'll be mainstreamed. That means a flood of intellectuals. A big worry I have is, Are they going to think about policy in the way that the public policy and the planning and the econ department and the poli sci department think about it, or is it going to be at the much broader level of how society creates disability, et cetera? You need both, because you can stay at such a large high plane of understanding, the social creation of disability, but then you don't worry much about how you do it. It's pretty hard to turn all of society around. The law does part of it very effectively. But you need a lot more targeted policy intervention.

And I'm going to feel much better when I see more individuals with disability wanting to do degrees after their disability studies courses at the undergraduate level in economics and public policy and some of these other places where I think you get to be sluggers in the long run on the policy issues and not just at the academic conferences. We need more DREDF-type organizations in all these areas--quite seriously, as opposed to--I would hate to see us just become a study of disability rather than a, "Here's what to do to make life more feasible and richer for people with disability," and with a very strong policy design and advocacy bent. I think the latter is also needed, but a combination of research with that.

Future of Disability Programs and Politics

Collignon: In the long run, where is disability going? Like a lot of other programs that affect particular groups, we're now at a stage where it seems to me that at the federal and state levels persons with disability are increasingly being looked to as "Well, they have to lead their own programs." And that's, I think, a political change. It's still not there all over the place, but it's certainly much more than it once was. That's a period that I think lots of programs go through over a long period of time. And the challenge is going to be to make sure we have good program managers, good lawyers, et cetera, who can then do that over time. That clearly mainstreams.

I suspect there will be a reaction in some places against the cost of some of the things we have wanted to do. Most of us have usually used the argument, "Wait a minute. Don't invest in institutions; invest in independent living services, invest in employment services. They're going to help a person a lot more and will not be as much as institutions," and I think that's as solid an argument as it ever was. But I had an experience a week or two ago when a very prominent activist from the seventies and eighties who has had some major roles at the federal and state levels and who was staying at my house--probably going through a big career crisis--but was fretting about whether all that work really had led to major change that was useful. And in fact they kept citing this example of \$100,000 to help a person with a severe disability to go into a mainline school, while in that same school there are all these classes that are grossly underfunded that are trying to help African-American and Hispanic kids gain an education and overcome some of the barriers that they're confronting in the central city ghettos and the rest.

The feeling is that some of the priorities were not straight. You get better priorities across the large population of people with needs. Well, I do worry if there are other reformers that are having that niche, then it means--and that person remains very much a left-oriented politician-type--that we may downstream have to do some new defenses of the kinds of gains that we've made, and there will be an effort to try, in terms of budget dollars, re-rationalize how we're allocating to different groups, to different kinds of service needs, what have you. We're going to need to have our defenses ready at that point, and to think broadly about how we deal with that.

We did a number of studies through the years for different states that actually ended up showing that coming from an African American background, living in a central city ghetto, was far more predictive--all other factors being controlled--than the severity and nature of the disability in determining their ability to get a job and that sort of thing. Some of these are significant further disabling conditions that a person who has a disability confronts. We're starting to look more: what do we do for African Americans or Hispanics with disability? But there is a need to rethink how to prioritize in terms of that.

And we ought to be, secondly, able at some point--I don't think we're ready yet; I think it's ten years down the line--to say, "Of the things we tried, what really worked and what didn't work? Is mainstreaming into a class, totally integrated with other kids, always the best way to go for an individual who has severe learning problems as opposed to more intensive specialized treatment that might have been more affordable, where they had integration part of the day but were removed part of the day? I don't know. All those things may come about in the re-debate.

What works in terms of education? What works in terms of employment interventions? I long argued that education was often a better investment for many people with severe disability who had the intellectual capability than the kind of quick job training and quick job placement--the latter tended to result in fairly fast job turnover and not very significant incomes or job gains over a career. The education, because it was taking advantage of all that person's skills, often resulted ten years later in much higher income levels for that person. States didn't like it because the education cost a lot more per year than did the quick job training program. But we might look and see what kinds of interventions work best for different individuals.

I think you always mainstream public transit, but is that the only way to go or isn't there a role for tailored transportation services for the person who calls up and says, "Come to my door"? The irony is that we at an earlier point rejected that in order for mainstreaming, but the whole transportation movement for the mainstream is now saying the general population is better served by demand-activated service, where you call up and--

Breslin: Demand response.

Collignon: Demand response, thank you. So all these things, in a way, we get to replay, and initially the main thrust was we wanted to make sure we were mainstreaming as much as it was that we solved the functional need. Some of these we may decide, okay, we can do our mainstreaming--we got to have it here, but frankly we want to solve the functional need better for more of us and the money we've got. I don't know the answers to all those; I just have the feeling that at some point we'll be able to ask and try to analyze those questions, but that's a decade off.

Breslin: You raise a number of incredibly interesting questions, but I think in terms of having a vision for the future, do you see any parallels between the rethinking of the priority areas that you just discussed and the strategies that are being used in the racial minority communities and particularly the African-American community to resolve systemic racism and poverty?

Collignon: That's very interesting. My perception is that at the academic level the reactions to the ethnic issue has been much more to cluster and resegment rather than integrate. That's my perception from what I hear from my colleagues. Not the poverty solutions, but in terms of their identity. I see some of that happening with various groups of people with disability where they try and sort of define themselves. You can argue independent living centers gave us our way of having a bonding among ourselves as had been fought for us individually and as groups to be more able to integrate in the mainstream. I think we, knock on wood, solved that identity issue sooner, before the other ethnic groups did. We found a way of doing it quickly. The independent living centers and those organizations, I think, were the way we did it, while still wanting to be mainstreamed. I think it would be a mistake not to want to continue to be mainstreamed under any definition.

The debates over poverty and strategy are going to continue. I would predict that in the future we are going to--as I see it happening--resurrect sheltered workshop facilities, not as places people necessarily retire to, where they're run by people with disability, where we try and move people out, but they're going to merge again, and they're probably going to merge again in the context of particularly having to do with the homeless. Those people who need a daycare kind of operation, who the employment folks don't even want to begin to pick up but want some work activities, something meaningful to do as they're back into that mode of interaction with other people than to move out into more traditional job training programs. My guess is that ten or fifteen years down the line I see that reemerging, but very different than sheltered

workshops in the past. But right now we call that still something like a sheltered workshop--the phrase "rehab facility" [being] the better way that they tried to recoin themselves. We need a better word than that, that's for sure.

Breslin: Community rehabilitation, I believe, is one of the terms of art.

Collignon: Better, yes. Much better. I see that one emerging. I think the kind of wage subsidy and similar programs that are debated also rise with disability. What we may want to recognize is that what worked for people with disability is not necessarily one and the same as what works for other kinds of ethnic groups. And the issue that the same policy should cover all, I'm not sure is something we want to sign on for. We may want to have policies much more targeted to our own particular situation.

Breslin: Are you, in general, in thinking about where you have come, where the movement has come, and looking into the next century which we're just about to be facing--are you generally optimistic or generally not optimistic about the future of the political movement and--

Collignon: Well, I'm probably an incurable optimist by nature. I've been accused of that. But yes, I'm pretty optimistic. I see how far it's come. I see much more integration today than I did twenty years ago, by far. I see a movement of people who know how to fight for their own kinds of requirements, and I see them institutionalizing that in different places--in law, in who controls the politics of various kinds of policy issues. I'm, therefore, a lot more confident that people with disability will be able to speak and fight for themselves and know how to be players in coalitions and all kinds of things that I think ultimately will work to their better.

Although I do believe government is obviously going through great changes, and you can't get either political party to be very bold anymore, and they're all principally worried about budgets and so forth, there will be some reinventing government, there will be some privatization and nonprofits and the rest that give us major new opportunities for our institutions. But I think we will be able to do it because we developed viable local institutions before many of the other groups, particularly the independent living centers and the other organizations that are out there that give us a leg out in developing centers that kind of knew how to do an awful lot with a very little bit of money while being very much reactive

to consumers, and which were often consumer controlled. So I think that part is pretty good.

I believe emphatically that we remain a group that has the empathy of the general population--not pity; less pity and sympathy than it once was, but it's more empathy. There's much more realization that Uncle Joe or Aunt Jane had a disability and we have got some linkages here in the way so many other disadvantaged groups have to confront. If you're African American, Hispanic, what have you, you've got an ethnic tradition, and unless there's more intermarriage it's harder to break down. I think there's much more identification with the larger disability movement which provides some political advantage and leverage to us.

There are some changes that are happening in the workforce that are much slower than people thought they'd be. I never dreamed--I remember when they said, "Oh, everyone will do their jobs out of their houses," and I said, "Yeah, probably not in my lifetime." But I do believe there will be a much larger, proportionally, workforce that will do that somewhere over the next twenty or thirty years with the advent of computers. And I think that certainly works to the advantage of a large number of individuals who have disability and who have all the intellectual capacity but merely have some physical impairments. I believe that that works very much in their benefit.

I think the groups that might have the largest dilemma are those with developmental disabilities. On the one hand, the computer may make it more easily accommodating of certain kinds of less skilled type work--that's the one thing I do think potentially is there. But the ability to simply stay in school and learn how to handle that--I'm not sure we still don't write off those with retardation much too early in life.

The one that will be the most difficult for us over time will still remain, I think, chronic mental illness because it scares people to death. All the surveys we ever did of employers found that was the group that employers found most hard to even dream of accommodating, because a person who looks like they're perfectly normal in their functioning and doing a great job for one month, and then for whatever reason--they go off their medication or have a new episode--and it just scares people to death. And I think that's tricky. On the other hand, we've learned so much about how to medicate and control--that's the positive side, I guess, of the medicine. But I don't think we know how to deal with the behavior associated

with disability other than try and control it through the medication. That leaves me an optimist. How about yourself?

Breslin: [laughs] Well, we'll have to discuss my optimism or lack of it when we're not on tape, I think. I'm mindful of the time, and I'm wondering if you have any last concluding thoughts for posterity.

Collignon: Keep going. That's probably my main concluding thought.

Breslin: Those are two wise words.

Collignon: Build community and keep going.

Breslin: I can't think of a better way to end this interview. Thank you.

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Disability Rights and Independent Living Movement Oral History Series

BUILDERS AND SUSTAINERS OF THE INDEPENDENT LIVING MOVEMENT IN BERKELEY
VOLUME IV

Hal Kirshbaum

DIRECTOR OF PEER COUNSELING AT THE CENTER FOR INDEPENDENT LIVING

An Interview Conducted by
Kathryn Cowan
in 1999

TABLE OF CONTENTS--Hal Kirshbaum

INTERVIEW HISTORY	161
BIOGRAPHICAL INFORMATION	162
Early Years and Education in New York, Ohio, and Berkeley	169
The Peer Counseling Program at the Center for Independent Living, 1974-1982	170
Moving to the Wright Institute, Antioch West, and the Union Graduate School	177
The Peer Counseling Process	179
Growth and Changes at CIL, 1974-1982	182
Reflections on the Independent Living Movement	184
Addendum: Autobiographical Essay	187

INTERVIEW HISTORY--Hal Kirshbaum

Hal Kirshbaum was interviewed for the Disability Rights and Independent Living Movement oral history project because of his role in the development of the peer counseling program at the Center for Independent Living.

Mr. Kirshbaum was diagnosed with multiple sclerosis in early 1964. He became aware of the value of peer counseling while teaching at Coe College in Cedar Rapids, Iowa. Hal and his wife Megan returned to Berkeley in 1974, and his interest in the disabled independent living movement led him to the Center for Independent Living. Megan Kirshbaum also came to CIL, and she began her own program, Through The Looking Glass, for parents and children with disabilities.

Because of his apparent fatigue, Mr. Kirshbaum was interviewed in one short session at his home in Berkeley, California, on March 18, 1999. The transcript was edited by the interviewer, who later returned to the Kirshbaum home to review the transcript. With his wife sitting in, Mr. Kirshbaum made several corrections to names and dates, and added a few sentences for clarification. In addition, he provided a short autobiography, which follows the interview transcript.

The Regional Oral History Office was established in 1954 to augment through tape-recorded memoirs the Library's materials on the history of California and the West. Copies of all interviews are available for research use in The Bancroft Library and in the UCLA Department of Special Collections. The office is under the direction of Willa K. Baum, Division Head, and the administrative direction of Charles B. Faulhaber, James D. Hart Director of The Bancroft Library, University of California, Berkeley.

Kathryn Cowan, Interviewer/Editor

March 2000
Regional Oral History Office
The Bancroft Library
University of California, Berkeley

Regional Oral History Office
Room 486 The Bancroft Library

University of California
Berkeley, California 94720

BIOGRAPHICAL INFORMATION

(Please write clearly. Use black ink.)

Your full name Harold Reis Kirshbaum

Date of birth 1/7/43 Birthplace Brooklyn, NY

Father's full name David Kirshbaum

Occupation Development Director Birthplace Patterson, NJ

Mother's full name Reba Kirshbaum

Occupation bookkeeper Birthplace Patterson, NJ

Your spouse Megan Kirshbaum

Occupation psychologist Birthplace Portland, Oregon

Your children Anya Kirshbaum; Noah Kirshbaum

Where did you grow up? Brooklyn, N.Y. + Washington, D.C.

Present community Berkeley, CA.

Education M.A., Philosophy, New York University

B.A., Antioch College Ph.D., Philosophy, U.C. Berkeley

Occupation(s) professor, Counselor, administrator

Areas of expertise philosophy, leadership

Other interests or activities photography, writing

Organizations in which you are active Through the Looking Glass

CURRICULUM VITAE

HAL KIRSHBAUM
801 Peralta Ave
Berkeley, CA 94707

510/527-3496

EDUCATION

PhD, University of California, Berkeley, in Philosophy, 1973

MA, New York University, New York, in Philosophy 1967

PhD Candidate, University Without Walls, Santa Monica, in Psychology, 1984

BA, Antioch College, Yellow Springs, Ohio in Philosophy and Religion, 1965

LICENSE

California State License to practice as a Marriage, Family, and Child Counselor,
#20167

INTERNSHIP

Post-doctoral clinical intern at the Infant-Parent Program, Dept of Psychiatry,
UCSF, Sept. 1984-June, 1985.

POST-DOCTORAL TRAINING

Infancy

Trainee at the Infant-Parent Program, Dept. of Psychiatry, UCSF, Sept., 1984-
June 1985

Training and consultation by Jeree Pawl, PhD, director of the Infant-Parent
Program, UCSF, (4 hours/month) 1985-92

Advanced Training in Infant Development, Frances Knudtson, MA, 1985

Psychological Development of the Infant At Risk, Frances Knudtson, S.F. State
University, 3 semester units, 1983.

NCAST training, certification, UCSF, 1986

Brazelton Neonatal Assessment Training, Brookside Hospital, 1985

Hypnosis

Hypnosis and Hypnotherapy, Milton H. Erickson, MD, several weeks in 1977
and 1978

Hypnotherapy supervision and training, Gerald Edelstien, MD, (weekly) 1979

Psychotherapy

I had wide and intensive training, supervision, and experience in psychotherapy over 16 years, including:

Training in Family Therapy Using a Social Learning Model, Mindy

Fullilove, MD, (monthly), 1986-89

Ethnic Diversity and Psychotherapy, Jan Faulkner, LCSW, 1980

Psychotherapy supervision, Jan Faulkner, LCSW, (weekly) 1979-81

Peer counseling and psychotherapy at the Center for Independent Living (CIL), Berkeley, 1974-82

Psychotherapy supervision, Bruce Africa, MD, Miles Weber, MD, and Steve Allen, PhD, (weekly) 1978-81

Ethical Issues in Mental Health, Miles Weber, MD, 1979

Brief therapy training, Lynn Segal, LCSW, from Mental Health Research Institute (MRI) 1979

Techniques of Couple & Family Therapy, SF Family Therapy Institute, 1976

Gestalt Therapy, John Enright, PhD, 1975-76

Physical Disability

I also had ongoing training, supervision, and experience at the Center for Independent Living in this field from 1974 to 1982 including:

Brain Damage and Organicity: Assessment and Therapy, Nancy Van Couvering, PhD, 1980

Ongoing neurophysiological supervision, Nancy Van Couvering, PhD, (weekly) 1979-80

Psychology of Deaf Culture, Hank Berman, MA, MFCC, 1979

Disability and Drugs; Head Injury and Communication; Physiology, Disability, and ongoing consultations, Sheldon Berrol, MD, 1978-79

Sex and Disability Counseling, Robert Geiger, MD -- as well as regular consultations with staff of Sex and Disability Unit, Dept. of Psychiatry, UCSF, 1975-77

Sex and Disability, UCSF Sex and Disability Unit, Berkeley, 16 hour course, 1975.

Substance Abuse

Physiology and Substance Abuse, Nathan Cope, MD, Santa Clara Valley Medical Center, 1979

Depression and Medications, Glen Elliot, MD, Santa Clara Valley Medical Center, 1979

Pharmacology of Drugs, Leslie Bragg, California Dept. of Alcohol and Drug Abuse, 1979

Substance Abuse and Social Systems, Steve Allen, PhD, Director, Mental Health Services, Contra Costa County, (weekly supervision), 1978-81

Pain and Medication, Robert Fink, MD, Herrick Hospital, Berkeley, 1979

PROFESSIONAL AND ACADEMIC POSITIONS

Member, Board of Directors, Through the Looking Glass; Agency providing services, professional training and conducting research regarding families with disability issues in parent or child. 1982-present.

Core Faculty, Graduate School of the Union Institute. 1978-1998
Academic and administrative responsibilities for doctoral learners (fully accredited PhD degree). Instrumental in the creation of a formal academic relationship between the Union Institute and Gallaudet University (in 1989) providing access to PhD degrees for persons with significant hearing loss. At the Union Institute Taught numerous seminars including one (in 1988) on Human and Child Development with Clark Moustakas, EdD, PhD.

Training Co-Director. National Rehabilitation Research and Training Center on Families of Adults with Disabilities, Through the Looking Glass. 1993-1994

Outreach Coordinator/Peer Clinician, Through the Looking Glass, Field Initiated Project, National Institute of Disability and Rehabilitation Research. Developing and evaluating impact of adaptive equipment . 1991-1993.

Clinician/Father Specialist, Through the Looking Glass; Clinical responsibilities included homebased intervention with fathers of at-risk or disabled infants and toddlers as well as homebased and group intervention with parents who are physically disabled, 1982-1991.

Field Advisor/Degree Committee Member, Antioch International, Antioch University . Academic responsibilities for students in the Individualized Master's Program for Antioch International, 1984-1990.

Co-principal Investigator for the first research on the interaction between physically disabled mothers and their able-bodied infants (funded by National Easter Seal Research Foundation), Through the Looking Glass, Inc., 1985-1988.

Member, Professional Advisory Committee of the Northern California Chapter, National Multiple Sclerosis Society, 1978-1991.

Member, Board of Directors, American College of Traditional Chinese Medicine. The College offered a Master's degree in Acupuncture, and a Doctorate in Oriental Medicine, 1984-1988.

Director of Disability Studies, Wright Institute, Berkeley. Developed and taught a program in Health and Rehabilitation Psychology: Disability Studies. This included the successful planning and implementation of private fundraising to obtain fellowships for physically disabled students, 1980-82.

Project Director, Counseling Program/Substance Abuse Prevention and Treatment Services, Center for Independent Living. This was a unique

counseling and psychotherapy program I conceptualized, implemented, and directed. I supervised a staff of 19 persons, 1978-82.

Director of Health Counseling at CIL. Administrative responsibility for peer counseling (individual, couple, and family), independent living skills counseling, medical counseling, and intake/followup counseling. Work with clients, supervision and training of peer counselors and doctoral candidate interns in psychology and rehabilitation. Training of 3rd and 4th year medical students from UCSF and Stanford Medical Schools, 1977-78.

Director of Development Office (CIL). Overall responsibility for development and public relations, 1976-77.

Counselor Coordinator (CIL). Developed the first peer counseling program around independent living for physically disabled persons and supervised (five) peer counselors under a HEW Rehabilitation Services grant, I trained persons from other states as well as from abroad who were interested in replication of the model, 1974-76.

Regional Director, Center for Health Studies. Duties included development of health related and social service PhD programs with Union Graduate School, MA programs with Antioch/West. Conceptualization and implementation of health programs -- including a Self-Care Learning Residence for physically disabled persons and an Institute for Health and Environmental Design with cooperation of staff from UC Berkeley, 1976-79.

Co-founder and program coordinator in charge of academic quality of the Joint Degree Program, Center for Independent Living/Antioch College (originally developed within the Center for Health Studies when I was Regional Director -- see above) . This program offered MA degrees in psychology and health services administration with an emphasis on counseling and serving people with physical disabilities: Disability Studies. 1975-78.

Founded program providing counseling services to physically disabled prisoners at Vacaville Prison. This program later had independent status as the California Disabled Prisoners Program, 1975-76.

Founder and Director of a program in the San Francisco Bay Area affiliated with the Institute for the Advancement of Philosophy for Children. Worked with local school districts and supervised doctoral students to develop programs to facilitate philosophical thinking in young children, 1975-80.

Instructor/Assistant Professor of Philosophy, Coe College, Cedar Rapids, Iowa, 1971-73.

CONFERENCES AND PUBLICATIONS

Parents with Speech Involvement and their Children. *Communication Outlook*, vol 15, no. 2, Spring 1993.

New Books: My Mum Needs Me. *Disability, Pregnancy & Parenthood International*, No.2. April 1993, review co-written with Megan Kirshbaum..

Disability and Humiliation. *Journal of Primary Prevention, Special Issue: The Humiliation Dynamic: Viewing the Task in a New Perspective*: vol. 12 #2, Winter 1991.

The Americans With Disabilities Act: an opinion. *The Network*, vol 2, #10, Winter/Spring 1991.

Presentation of paper on AIDS and Progressive Disabilities at Aids and Disability Symposium, September 28, 1991

Presentation of paper, "Issues of Services by Professionals with Personal Disability Experiences". 1987. National conference, Families & Disability: Family Systems Approaches Throughout the Life Cycle sponsored by SF State University, Through the Looking Glass,

Presented paper on Alternative Healing in Western Culture at the American College of Traditional Chinese Medicine, 1987.

Presented paper on educational discrimination of persons with physical disabilities to graduate faculty of Union Institute, 1987.

Theories of Infancy, Dissertation, Psychology, University Without Walls, Santa Monica, 1984.

Presented paper on Fathering and Physical Disability at the Disabled Men's Workshop sponsored by Community Resources for Disability and the Center for Independent Living, 1983.

Presentation on Alcoholism and Disability at the conference Alcoholism and Physical Disability sponsored by the National Council on Alcoholism and United Cerebral Palsy, 1983.

Presented paper on Clinical Services for Disabled Persons at the annual conference of the Northern California Chapter of the National Multiple Sclerosis Society, 1982.

Disability and Substance Abuse. In *Alcohol Health and Research World*, Winter Issue 1981, NIAAA.

Focus on the Family. In *MS Patient Service News*, Vol 21, #3, Winter, 1980.

Keynote Speaker at the National Chapter Conference, National Multiple Sclerosis Society, Denver, Colorado, 1980. Talk on New Directions for the 80's was partially reprinted in *International Medical News Group*, Sept., 1980.

Co-facilitated three-day conference for spouses of people with multiple sclerosis (June 1980) through the National Multiple Sclerosis Society.

Presented paper on The Disabled: A Newly Visible Minority, and organized a two-day workshop on Substance Abuse and Disability with the California Health Training Center of the State Department of Mental Health at Ralph K. Davies Medical Center, San Francisco, Jan.31 & Feb.1, 1980.

Contributed chapter to *Consumer Education in the Human Services*, edited by Alan Gartner, Colin Greer, Frank Reissman. Pergamon Policy Studies, New York. 1979.

Presented paper on The Psychological Aspects of Multiple Sclerosis at the annual conference of the Northern California Chapter of the National Multiple Sclerosis Society, 1979.

Disabled Consumer as Enabled Producer. In *Social Policy*, Vol. 8, #3, Nov., 1977

Contributor to section on Mental Health Issues of People with Physical Disabilities in *Mental Health Plan*, Alameda County, California, 1977.

Organized and co-directed a conference on the Psychological/Psychiatric Aspects of Physical Disability at the Wright Institute, Berkeley, 1976.

The Center for Independent Living: A Community By and For the Physically Disabled. In *Social Policy*, Vol. 7, #2, Sept./Oct., 1976. Co-authored with Dominic Harveston and Alan Katz.

Presented paper on Innovations in Training and Education: New Approaches in the Field of Rehabilitation of People with Physical Disabilities at the National Conference on the State of the Art of Independent Living, Berkeley, 1975.

INTERVIEW WITH HAL KIRSHBAUM

Early Years and Education in New York, Ohio, and Berkeley[Date of Interview: March 18, 1999] ##¹

Cowan: This is an interview with Hal Kirshbaum. It's March 18, 1999.

Hal, would you like to say a few words about your early background, where you were born, and something about your parents?

Kirshbaum: I was born in Brooklyn, New York. My parents were involved with the labor unions back in the thirties and so on, and the forties. Then they owned a store. Then we moved to Washington, D.C., when I was around eight or nine. We just stayed there until I went on to college, after high school.

When we lived in Washington, I was the only white in an all-black gang. It was unusual, but that's how my early experience had been.

Cowan: In high school?

Kirshbaum: Well, before high school, and high school.

Cowan: After high school, you went on to college?

Kirshbaum: After high school, I went on to Antioch College in Ohio and went on from there. Then I went back to New York. I got my master's at New York University. Then after that, I went to UC [University of California] Berkeley. I got my doctorate in 1973.

Cowan: So you came out here to go to school?

Kirshbaum: Yes, came out to go to college.

¹## This symbol indicates that a tape or tape segment has begun or ended. A guide to the tapes follows the transcript.

Cowan: What did you get your degree in?

Kirshbaum: It was in philosophy.

Cowan: What year did you come to Berkeley?

Kirshbaum: I think that was around '67, '68, around that time.

Cowan: Was Berkeley quite a contrast?

Kirshbaum: It was quite different then than anything I'd experienced before. And certainly different from New York and so on. Then I got involved with the civil rights and all the various antiwar and variety of movements in the West. I went on the march on Washington and all that stuff during those years.

Cowan: You were involved in that?

Kirshbaum: Yes. I did a variety of marches and just different--you know, political things.

The Peer Counseling Program at the Center for Independent Living, 1974-1982

Cowan: Well, what brought you to CIL [Center for Independent Living]? What attracted you to the organization?

Kirshbaum: I was teaching in Iowa, actually, after college, after I finished my doctorate. I got to know Jim Campbell, one of the faculty there, who had severe kidney disease. He and I started to talk, and since I had been diagnosed already with MS [multiple sclerosis] early on, even though I was showing nothing at that point, we got to know each other pretty well. I learned about the importance of peer counseling then. I didn't know about CIL until we returned to Berkeley for Megan to get her Ph.D. in 1974.

Cowan: Did you think you wanted to go to work there?

Kirshbaum: I had no idea when I came back to Berkeley.

Cowan: But at some point, you did go to work there.

Kirshbaum: Yes. I actually started the peer counseling project at CIL when Ed Roberts was still the director.

Cowan: Did you apply for the job, or did you offer to start the program?

Kirshbaum: I started it.

Cowan: It was your idea to start it?

Kirshbaum: Yes.

Cowan: Did you approach them?

Kirshbaum: Well, I had been doing a variety of things around disability issues and talking to people one on one, and it sort of grew by itself out of that. So I said, "Why don't we just do a whole program on that?" The motivating force was there was some money available through the federal government, some grant monies available, which I applied for and got. We went from there.

Cowan: You applied for the grant?

Kirshbaum: Yes.

Cowan: And who did you go to at CIL to suggest it start there?

Kirshbaum: It was to Ed Roberts, who was directing the program.

Cowan: What did Ed think of the idea?

Kirshbaum: He liked it. He thought it was a great idea.

Cowan: So he hired you as a CIL employee?

Kirshbaum: Yes.

Cowan: And the grant money--?

Kirshbaum: Came from the federal government. I mean, that was the way it was handled. The monies came from there.

Cowan: How did you start peer counseling? What was going on at CIL? How did you get it going?

Kirshbaum: I have no idea--I don't know. It wasn't quite that organized. It was kind of informal. Just one on one, talking to a different variety of people. There was nothing like this before. I went through a variety of forms of training--because I had never done counseling or psychology or anything like that before. We started to do that.

Oh, one of our first trainers was a man named Peter Leech. He was a therapist and a counselor and social worker. We just went from there.

Cowan: He trained you?

Kirshbaum: Yes, I got training from him. And then with my wife, Megan. Megan said, "How come there's nothing here for families?" So he said, "Well, start it." And she did. So she started the first family counseling.

Cowan: Was that right away, or several years after the peer counseling program began?

Kirshbaum: No, it was about a year after.

Cowan: Who were your clients in the beginning? Who came to you?

Kirshbaum: Oh, just a variety of people, with a whole variety of disabilities.

Cowan: Did you notice that men came more than women, or women came more than men?

Kirshbaum: Not particularly.

Cowan: What would you say some of their main concerns were?

Kirshbaum: Well, there were issues about what was disability? What's going on here? Was it just being treated as somebody sick, or somebody who didn't want to be noticed, or--? We were trying to create peer counseling as an entity, as a group of people who had something in common but weren't defined by being ill or sick or someone to be avoided. Those were, I think, the primary concerns.

Cowan: What was your answer to that, what is disability?

Kirshbaum: I actually don't know.

Cowan: Do you know today?

Kirshbaum: I have no idea. Now I probably know even less than I did then, or thought I knew.

Cowan: Well, what would a typical day be like for you at that time?

Kirshbaum: Well, there was a bunch of administrative tasks and headaches like that, and taking care of different individuals and their

time sheets and so on. But then I would also run some groups of individuals who would come in for counseling or talking. If they wanted to discuss progressive illnesses, then I could pretend that I knew about it. I had no idea what it was, but I had done a whole bunch of reading in it, so I could answer some questions or talk about individuals lives and so on.

Cowan: Besides progressive illnesses, what other groups can you think of?

Kirshbaum: Oh, there were some with spinal cord injury. There were quite a number of them. They tended to be young men, because that's how they became spinal cord injured: they were athletes and so on. So there were a variety of broken necks and broken backs and so on like that. And there were some individuals with cerebral palsy, a whole variety of things with different kinds of effects.

We hadn't started the parenting group. That was something that my wife did, and her program, which was in Berkeley, called Through the Looking Glass, was designed around disabled parents and their able-bodied--their often able-bodied--children and how that could be dealt with. Because disabled folks weren't supposed to be parents at that time. I hope that's changed.

Cowan: People with similar disabilities had groups, as well as individual counseling?

Kirshbaum: Right, right.

Cowan: Besides you, who else did counseling?

Kirshbaum: Well, there were people there. There was someone named Dominic Harveston who did some counseling there as well. God, I can't remember the names of all those staff. There's different individuals--it was too many years ago.

Cowan: Were you the director of that program?

Kirshbaum: Yes, of the counseling program.

Cowan: And who worked under you?

Kirshbaum: Well, all the different counselors there. I think at some point there was up to fifteen, nineteen--something like that--individuals who were doing a variety of counseling work. It grew incredibly, exploded like a mushroom. It took a few years, but it grew very fast.

- Cowan: The counseling program, or CIL in general?
- Kirshbaum: Well, all of it, CIL and the counseling program within it.
- Cowan: What would you say was the reason for that?
- Kirshbaum: Well, it was addressing really an unmet need. Disabled people were beginning to get their voice, beginning to be heard around. There was something about this area that seemed to attract that population.
- Cowan: I have heard that Don Galloway--
- Kirshbaum: Oh, yes, he was my boss in that very first peer counseling project.
- Cowan: Was peer counseling called R&D or research and demonstration?
- Kirshbaum: The funding came from the Research and Demonstration Projects.
- Cowan: And were there other projects under that, or just peer counseling?
- Kirshbaum: I have no idea. That's the only one I cared about.
- Cowan: Do you have any recollection what CIL was like at that time? Where was it located?
- Kirshbaum: When I first connected with it, it was upstairs in an office building on University Avenue in Berkeley. As it grew, and as more and more people needed more and more space, CIL got an independent spot where they're located now.
- Cowan: Would you say your program was one of the most successful programs at CIL?
- Kirshbaum: Yes.
- Cowan: Do you remember other programs there?
- Kirshbaum: I didn't pay any attention to that. I mean, one of the projects that grew out of it was the computer training program, and that became an independent program fairly early on. I didn't have much contact with them.
- Cowan: Do you remember what the atmosphere was like at CIL?
- Kirshbaum: What do you mean?

Cowan: Well, was it energetic and bustling, a lot of people around, or--

Kirshbaum: Yes, all of the above.

Cowan: Were people getting served in the way that you thought they ought to from your program?

Kirshbaum: Yes, well, there were a lot of lacks. A lot of things couldn't be done. Streets weren't ramped, you couldn't get around the different spaces. When they could get to us, then they could get some--they could talk to a variety of folks. But it wasn't easy to get to us. There was no transportation. It was kind of piecemeal. So there was a great need to make the environment accessible.

Cowan: How did you get word out about your program?

Kirshbaum: Well, through newspaper articles mostly, and word of mouth. There wasn't a very organized process. I mean, there was an attempt to do that, to do some public relations and do some of that and to dispense information, but it was hard to do.

Cowan: Was that an attempt on your part or on the organization--I mean to make your program known?

Kirshbaum: No, it was the whole organization. Well, I wasn't very involved with that. To get it known.

Cowan: Well, how do you think a typical person who came for counseling, how do you think they found out about you?

Kirshbaum: Well, either word of mouth, maybe somebody they knew, their physician, maybe they read about us in the paper. I really don't know, outside of that.

Cowan: Besides just that definition of disability and--was there a typical concern? Was there something, do you think, that was on everybody's mind?

Kirshbaum: No. Not outside of that. Just to get known, just to be considered as a real human person, not ignored any more. Say, "I'm here, we're here, notice us, we're a part of this." That seemed to be the primary issue.

Cowan: Did people come over a length of time? They came again and again for counseling?

Kirshbaum: Yes, usually they would spend some time, yes.

- Cowan: Did minority groups--were there people of minorities who came in for counseling? Was that an additional--
- Kirshbaum: Yes, that was an additional--some people did. In fact, I think one of the leaders of the program was a black man, can't remember his name. But that was an issue that came up also, and one that would be addressed whenever it would arise. There was a program, I think, at the independent living center in Oakland.
- Cowan: I think there were a number of things that grew out of CIL.
- Kirshbaum: Yes, yes, just a variety of things.
- Cowan: Ed Roberts was still the director when you came. But he left then, is that right?
- Kirshbaum: Right. He went on to the state.
- Cowan: What did you think of him as a director at CIL?
- Kirshbaum: Well, I thought he was very good. Very powerful. People listened to him. He got things done. I don't know quite how he did it, but that's okay.
- Cowan: Do you have any ideas on how he did it?
- Kirshbaum: I have no ideas, no.
- Cowan: Well, do you think people felt your program was successful?
- Kirshbaum: Oh, yes, I think it was. I think people felt better, they felt more involved and connected.
- Cowan: Did you provide assistance in any other way?
- Kirshbaum: No. We would motivate them to provide their own assistance. If they needed something, they had to do it.
- Cowan: Were they people who had come from the Disabled Students' Program?
- Kirshbaum: I think that's how it started. It came out of the Disabled Students' Program at Berkeley. But that was just in the beginning, and later they came from everywhere, all over.
- Cowan: Your clients.
- Kirshbaum: Yes.

Cowan: So eventually did people specialize? Did you see mostly people with progressive disability diseases, and someone else saw--did you have anything like that?

Kirshbaum: No, not particularly. In fact, that was debated as to whether or not it was useful to talk to folks who were more like you or talk to people who were different than you. But that was never resolved. It was just talked about.

Cowan: What did you think?

Kirshbaum: I think it's useful to talk to people who are different.

Cowan: Why?

Kirshbaum: Because they can--I don't know, they just see a variety of ways to go with it. And they can see, well, you can do this, and you could do that, even if you are different and so on. The danger of seeing too many the same is it can be segregation, a form of that, narrowness. And it was narrow enough as it is, disability is narrow.

Cowan: Do you mean that then people with spinal cord injuries would be separate from people with--

Kirshbaum: Yes, they were. But then I don't think it's very useful.

Cowan: So everybody--you counseled in every area of disability.

Kirshbaum: Yes, right.

Cowan: Is that program still going on today?

Kirshbaum: Maybe. I don't know. I've not been in touch with that.

Moving to the Wright Institute, Antioch West, and the Union Graduate School

Cowan: When did you leave CIL?

Kirshbaum: I worked for CIL until 1982. I was also director of disability studies at the Wright Institute in Berkeley. Because I was interested in creating a doctoral program in disability studies there. They had that program until 1982. Then, of course, the Wright Institute decided not to go with disability studies. So they didn't offer it after the first few years.

- Cowan: The Wright Institute?
- Kirshbaum: Yes. They used to offer a degree when I was there.
- Cowan: In disability studies?
- Kirshbaum: Yes, as part of a degree in psychology. But they're not doing it any more.
- Cowan: I don't know anything about the Wright Institute. What is it?
- Kirshbaum: Well, they're a psychology, psychotherapy primarily, Freudian and psychotherapy program within Berkeley.
- Cowan: So they're an educational--
- Kirshbaum: Yes, an educational process. But that's only--I was always interested in educational issues, so that was my major draw. But it didn't go very far.
- Cowan: So you went from CIL to the Wright Institute?
- Kirshbaum: Well, I put it--yes. We were involved and, yes, I went to the Wright Institute after that, in 1982.
- Cowan: I heard that there was some effort to establish a link between Antioch College and CIL.
- Kirshbaum: Yes. Well, Antioch had an interest for a while. Antioch West, which was in San Francisco. In 1975, I started a disability studies program at Antioch West. It was a joint program between Antioch West, the Center for Health Studies, and CIL. The program fizzled out after a few years. I can't remember when it finally stopped. They stopped doing programs around disability.
- Cowan: It sounds so interesting.
- Kirshbaum: Yes, I thought so.
- Cowan: Did they never offer degrees, or did they offer for a while and then stop?
- Kirshbaum: Yes, it was offered for a while. There were degrees that were offered, but it just petered out. I don't quite understand why, but they just didn't go anywhere.
- Cowan: Did you do that on your own or with someone else?

- Kirshbaum: Primarily on my own. But there were other folks who were involved. I never did anything by myself. There were other folks involved who were interested in parts of it, different aspects.
- Cowan: Who took your place when you left?
- Kirshbaum: God, I don't even know who's the head of the counseling program at CIL now. I should know the name. The program did go on. It's been going on and on for a long time.
- Cowan: But someone took your job.
- Kirshbaum: Yes.
- Cowan: So you were completely removed from CIL when you left?
- Kirshbaum: Yes, I left. I did other things.
- Cowan: Did you stay in touch at all?
- Kirshbaum: Just with some individuals, and with my wife.
- Cowan: She was working there?
- Kirshbaum: No. She left at the same time to start Through the Looking Glass, in 1982.
- Cowan: And after that?
- Kirshbaum: Then I was doing primarily educational things with the Union Graduate School, which is a doctoral program. It's called the Union Graduate Program. They're a national Ph.D. only degree, and there are individuals all over the country involved with that, actually internationally. I think there are some in Canada. They would offer courses or seminars, and I taught some of those as well during that time.
- Cowan: Yes, went on to education.
- Kirshbaum: Right. That seemed to draw me, yes.

The Peer Counseling Process

- Cowan: Well, back while you were at CIL and in the peer counseling program, how did people get matched up with counselors?

- Kirshbaum: Well, primarily we would talk about who wanted the particular clients or had the most to offer to individuals who wanted counseling. So it wasn't accidental, but there was just a variety of ways.
- Cowan: So a person would just show up at CIL and say, "I've heard about your counseling program"?
- Kirshbaum: Right.
- Cowan: And then what?
- Kirshbaum: They might be interviewed by an intake counselor. Actually, my wife sort of created their intake process, because she was convinced that there had to be a starting point that directed a person to the right spots, because otherwise, they would get lost. So there would be an intake process. And then in there, they would be connected to whoever was available or who had an interest.
- Cowan: And what does peer counseling mean?
- Kirshbaum: Well, peer--it's really somebody who's had some of the same experiences, either direct or through the family. It's not one to one, it's not real strict. There's a variety of ways it can happen. But the assumption is that there is some understanding, and it's not simply theoretical understanding.
- Cowan: So peer counselors had a disability of their own.
- Kirshbaum: Often, yes. Either they themselves had one, or they may have a family member. Like my wife who ran the counseling program for parents who had disabled children or a disabled spouse or disabled--you know. And she would be considered a peer.
- Cowan: Was that your idea in the beginning when you thought up this program?
- Kirshbaum: I wasn't that organized. It just evolved. It's sort of organic.
- Cowan: So you thought of counseling when you thought of this program, but the peer part was not part of your original idea?
- Kirshbaum: Well, peer was a part of it in the sense that there had to be some common experience. There had to be something in common. Otherwise, it was too theoretical, the counseling. I had had some of that, and I'd seen that often given to others, and it could be useful, but it was different.

Cowan: Was CIL the only independent living center that you know of that was offering this?

Kirshbaum: Yes.

Cowan: So it was studied?

Kirshbaum: Right, right. And it was really the first, and then it blossomed. There's millions of them--well, not millions, but there are quite a few all over the place.

Cowan: Did people come to you to ask how this program happened, or to ask you how to do their own?

Kirshbaum: Yes. We were visited by people from other countries even, as to how to create an independent living center. I think some people from Japan came, and some people from other countries as well. And they would say, "How do we do this?" I was probably not very helpful, but nevertheless, they could create it themselves.

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Cowan: So you were just saying people came from all over the world to look at the program. At peer counseling in particular, or CIL's in general? Both?

Kirshbaum: Both. At CIL's, but they were interested in peer counseling. They didn't know what it was any more than we did, and they were in the same process of creating it.

Cowan: Did you ever go anywhere and help set one up?

Kirshbaum: No. Later, I visited a few in different countries as part of the Through the Looking Glass program. I think I visited one in Sweden. And I could give informal information to the people involved, but I personally didn't set any up.

Cowan: Did you write papers saying, "Here's how to do it"?

Kirshbaum: I don't think "here's how". I don't think that's what we did.

Cowan: Well, you started at CIL in 1974, and you left in about what year?

Kirshbaum: Well, I think around 1982.

Cowan: Did you notice any difference in what people who came wanted or needed in counseling over that length of time?

Kirshbaum: No. Just as they got older, there were older issues. First, how do you meet girls, right, and then how to have kids, and then how do you--what do you do with children. I mean, it was pretty down to earth. It was just the progression through life.

Cowan: Did that question of identity change over time?

Kirshbaum: Not really. That always stayed.

Cowan: That was the one. And did I ask you how you answered that question?

Kirshbaum: People would ask me, but yes, I think you did. But I'm not sure how I answered anything like that.

Growth and Changes at CIL, 1974-1982

Cowan: But things changed a lot over those years, did they not, from '74 to '82?

Kirshbaum: Oh, yes.

Cowan: What things do you think changed?

Kirshbaum: Well, there was a blossoming of the number of people who were recognized as disabled, and the disability people were recognizing themselves as a force and having something significant to say, powerful as a group. And I think that grew, and it's still growing.

Cowan: Why do you think so many people came to Berkeley?

Kirshbaum: Well, it's pretty. [laughter] I don't know.

Cowan: Who do you remember as being real leaders in CIL, besides Ed?

Kirshbaum: Besides Ed? Well, certainly early on, Judy Heumann was a leader. She became part of the Clinton administration and went on to that. I think Don Galloway was, to some degree. What's the blind guy's name?--Jeff Moyer. I think he was a leader of the blind contingent, with other folks.

Cowan: When you got there, were there services for everyone? Or was it mostly for people with spinal cord injuries? Had the services expanded?

Kirshbaum: Yes, it was just a variety. For everybody. CP [cerebral palsy], spinal cords, MS, you know, a variety.

Cowan: What did you think of the leadership style? Do you think everybody was doing a good job? Were some better?

Kirshbaum: No, not necessarily. There was a great deal of incompetence and silliness and just passing time. I mean, if anybody got served, it was maybe by accident. I don't think it was coordinated well.

Cowan: And why do you think that was?

Kirshbaum: I don't know. I mean, it was both a lack of leadership--well, I don't know. People didn't know what they were doing. I certainly didn't know what I was doing. And nobody else knew, either, because they were just in the process of creating it. It was brand new.

Cowan: A certain amount of that is just true of new things.

Kirshbaum: Yes. I think it happens, because people don't have anything to guide themselves by.

Cowan: Well, what about political activity? You were politically active before you came. How about while you were there?

Kirshbaum: While we were there, we did that. I mean, there was a demonstration in the federal buildings.

Cowan: The 504 sit-in?

Kirshbaum: The 504 demonstrations. We were involved with all of that stuff.

Cowan: You particularly?

Kirshbaum: Yes, I did some of that.

Cowan: You did? Did you go to that sit-in?

Kirshbaum: I was involved--yes, I was at that sit-in. My wife was more involved behind the scenes. We divided things up.

Cowan: You said there was a program at CIL for families--disabled parents with children, and parents with disabled children. Is that two separate programs?

Kirshbaum: Well, there were two different focuses in the counseling department. Megan would be able to tell you more about that. That work grew into Through the Looking Glass.

Reflections on the Independent Living Movement

Cowan: I wanted to just ask you on your reflections on the movement in general, on the independent living movement. Because you certainly were there at a time to see people come from institutionalized living sometimes to living on their own. How do you think that happened?

Kirshbaum: I don't know why it happened. I mean, it's a mystery to me. But it was, I think, the right direction to go in. It was very forceful. I don't know.

Cowan: Was there anything special about Berkeley that encouraged it?

Kirshbaum: Well, Berkeley is always pretty aggressive and forceful and pushy and must have attracted a certain group of folks who had certain ideas about what they wanted. But no, I'm not sure. I mean, it could have happened anywhere, as far as I can tell.

Cowan: But it didn't.

Kirshbaum: But it didn't. It happened here.

Cowan: Well, actually, similar things did happen, but not with the impact, I think.

Kirshbaum: Right, right.

Cowan: What attracted you to Berkeley?

Kirshbaum: The school, but also the politics. The political stuff attracted me too. Actually, the overriding factor was the school, because I was interested in some of the people teaching what I wanted to study, and they happened to be at Berkeley. I didn't know anything about Berkeley at that time, so that's what moved me here.

Cowan: Well, that political activity that you found attractive, do you think that was a factor?

Kirshbaum: Oh, yes. It was. I mean, that's one of the draws.

- Cowan: In terms of seeing things change over the years, in terms of the environment, what changes have you seen?
- Kirshbaum: There's a great deal--incredible accessibility issues. I mean physical changes have occurred. And people are somewhat apologetic if they're not accessible, which is--I think it's significant. That's a big deal. I've seen that happen, and people are quite aware of the force of that happening. That I think you can leave directly at CIL's door--they did it. That's happened.
- Cowan: You mean in terms of removing physical barriers?
- Kirshbaum: Barriers, both physical barriers and cultural, attitudinal barriers. Seeing that people with disabilities can be effective as well as getting into physical spaces.
- Cowan: In terms of prejudice and discrimination, have you seen that change?
- Kirshbaum: Some, yes. I mean, people are still prejudiced, of course. That's still a--yes. But some of the more overt discrimination has been removed or it's maybe embarrassing or--it's going to take a lot of time for all of that to be effective.
- Cowan: Yes. Have you had personal experience with--it's easier for you to travel now, for example, or have you been to other communities where you felt it wasn't as open?
- Kirshbaum: Maybe so. Maybe it's a little easier now, because the attitudes of some of the individuals. But it's hard to know, because it's hard to compare it. I don't really, because I didn't have that experience.
- Cowan: What would be your thoughts on CIL just overall, if you were going to reflect on it?
- Kirshbaum: What do you mean?
- Cowan: Well, would you say it was an organization that served the community in the way it meant to, that its goals were fulfilled?
- Kirshbaum: I would think so. I think it was an effective organization. There's a lot more to be done, of course, but it has had an impact, I think.
- Cowan: Do you think it's as effective today as it was earlier? Do you think it's changed in that way?

Kirshbaum: I don't know. I'm not sure.

Cowan: Well, the disability community today. Is there a community?

Kirshbaum: Well, there is a community. There's a group of folks that are known and that people identify with. And there's a community in the sense of being able to recognize people and so on. But I'm not involved with any organizations.

Cowan: Were there some things at CIL that, looking back, you wish you had done?

Kirshbaum: I'm sure. I don't know what specific, though.

Cowan: Was it completely open to anything? If you had thought of anything at the time, would you have been able to start it?

Kirshbaum: Yes. Well, I wouldn't have had trouble overcoming any resistance. It was really open, because folks--it's the same way anything new is. It's like you don't know what to do, so you can do anything, pretty much.

Cowan: So the leadership was just open to anything.

Kirshbaum: Yes.

Cowan: Were any leaders more resistant than others to new ideas?

Kirshbaum: No, not as far as I know.

Cowan: They all said, "If you can think of it--"

Kirshbaum: "Do it. And leave me alone."

Cowan: Did you have any difficulties getting funded, your particular part of your program?

Kirshbaum: No, at that time, I think disability was becoming popular in the federal government. So for a time, there was some money available. That was okay for a time. But things like these change all the time, significantly. Like my wife, Megan, right now is going through a process of funding around parenting issues, and for a while that's been popular, but she's scared, and I don't blame her, because it might not be so popular any more. And the same thing around different kinds of disabilities. It's all political stuff, as to where the votes are, or whatever.

- Cowan: Do you think the ADA [Americans with Disabilities Act] is going to make a difference in that way?
- Kirshbaum: I would hope so.
- Cowan: Do you notice anything?
- Kirshbaum: Well, people will mention it, and being scared of it, or some of the legal folks, but I don't know. I really don't know what it's really going to do.
- Cowan: It's still early.
- Kirshbaum: Yes. And maybe folks might be clever enough, they figure ways around it. I don't know. The way it's written, it's pretty powerful, it's pretty direct. But we'll see.
- Cowan: Do you have any final thoughts?
- Kirshbaum: Not really.
- Cowan: Well, we'll just end it there then, and I thank you very much, Hal, for answering my questions.
- Kirshbaum: Okay, good.

Addendum: Autobiographical Essay ##²

- Kirshbaum: I grew up in two very different environments. Until I was eight, I lived in Brooklyn, in a very poor working-class Jewish neighborhood. My parents had always been politically active in the labor movement and were secular, self-educated, radical Jews. After Brooklyn, we moved to an all-black ghetto neighborhood in Washington, D.C. When we moved there, and for a few years afterward, Washington schools were segregated. In fact I couldn't go to the school across the street from my house, and had to travel to the "white" school several miles away. My strategy for survival in that black neighborhood was to become a member of the street gang that roamed there. I was the only white person in the gang and had been more or less "adopted" by a group of gang members--they were a "squad" in that militaristically self-defined social club. This group of

²This addendum was written by Hal Kirshbaum in 1982 or 1983 as part of his application for a Ph.D. program in psychology.

kids also provided me with some protection against the occasional open hostility of other gang members towards me as a white kid. In this gang I participated in normal street activities (petty theft, rumbles, mischief), shared the sense of group pride, and learned the street skills of the members. As a white in an openly racist society, I not only felt the hostility of certain gang members, but also experienced first hand the bigotry of white society. On one occasion, a group of us were caught shoplifting in a downtown store. Before the police arrived, the owner sent me home saying, "What's a boy like you doing with them." My friends went to juvenile hall and several of them continued on the road to serious crime. That lesson has stayed with me and was part of my motivation to become politically active in the civil rights movement--at least in the early sixties when whites were welcomed. I was involved in numerous demonstrations and protests that helped to form that movement--from being arrested in Ohio to organizing the Antioch College contingent to the 1963 March on Washington.

Another part of my political and social involvement in those years began as soon as I arrived at Antioch College in 1960. This was partly due to the fact that Antioch was on the cutting edge of the various movements and social changes that developed and grew during the sixties. As a freshman, I was in the last "legal" trip to Cuba from the U.S. until many years later. While we were in Cuba, the U.S. broke off relations with the Castro government. The Cubans busily prepared for the invasion that followed at the Bay of Pigs only a few months after we left. My experiences and observations of Cuba left a lasting impression on me. I long to visit again to see the changes and adjustments the people there have made.

During this time, I was also going through huge personal changes--even my academic interests continued to shift from science to philosophy. I've often wondered how this might have been affected by my medical status. In 1964 I was hospitalized with suspicion of a brain tumor. After a week of medieval tests, the physicians decided I had multiple sclerosis. Since I was only aware of MS through the pitiful portrayals on TV, I decided to read as much as I could about it. As part of one of my Antioch work-study jobs, I had ready access to a medical library. I succeeded in scaring the wits out of myself. It's only in the last seven or eight years that I've been able to adequately criticize the faulty research about MS that filled the medical literature in the sixties. At that time, I could only assume that I had perhaps ten to fifteen years to live and that many of those years would be as a helpless "invalid." As time passed and I did not get helpless as the literature

suggested, my doubts about the knowledge of the medical profession grew.

My general reaction to the MS was at first sheer denial. For although I did modify my professional plans--away from needing to use physical skills toward purely intellectual ones --I vigorously went on with my life. I attended graduate school in philosophy, getting my Ph.D. from the University of California at Berkeley. I was in Berkeley from 1967 to 1971 and besides pursuing my studies, became very involved in radical politics on campus.

In 1968 Megan Light and I were married. At that time we were both graduate students at UC Berkeley. We had known each other since we first met at Antioch in 1960 and had gone together--off and on--during all that time. Megan and I have since been involved jointly on several projects, and I think our personal relationship enhances our work together.

Although by the early seventies teaching jobs in philosophy were largely mythical, I managed to land one as an assistant professor at Coe College in Cedar Rapids, Iowa. Since I certainly did not know how long I could work, the appeal of this position was very strong. Megan and I spent three years there. Our daughter Anya, a wonderful, bright, feisty child, was born there. Iowa was not the stereotyped, dull, backward place we'd been led to expect. However, despite its variety and interest, three years were about all we could take. In 1974 I quit my teaching job at Coe and Megan, Anya and I moved back to Berkeley. We arrived with no jobs, but felt we could find a way to survive. It was clear that we needed to choose where to live and not let the scarce availability of jobs decide that for us. This also gave Megan greater professional opportunities, as her Union Graduate School committee members lived around here as well.

At first we lived in welfare, and I began to get involved with the fledgling disability movement at the Center for Independent Living (CIL) in Berkeley. A year later, grant money through this program began to be available to us. My personal interest and the social importance of the disabled independent living movement were clear. I got involved with the peer counseling section and started learning the techniques and skills needed for this. My new ability to cope with the reality of my own illness actually originated before my involvement with CIL--while I was in Iowa. Megan and I got to know another faculty member and his wife who were also dealing with illness and disability. He had kidney disease and we found--for the first time--that we could all laugh, joke, and

be human about our "illnesses" and not be either totally grim or completely inspirational all the time. In Berkeley, with the emerging CIL, I could see the potential power of people, often seen as "in-valid" and helpless, working together on common needs outside the pathologically defined categories imposed by the able-bodied world. I went from denial of my MS in the earlier part of my life to a deep involvement with the disabled independent living movement in general. This has taught me how to use the basic facts of what I am to struggle against the stereotypes of others who try to define me.

During the middle and late seventies I got more connected to this movement and work--primarily around the emotional aspects of disability. From 1974 to 1976, I functioned as a counselor and learned a good deal about the skills and techniques of therapy and family counseling. Between 1976 and 1982, I supervised, taught in, and directed the counseling program at CIL. This involved administrative and fundraising activities as well as direct clinical work. During this time I continued to use and develop my academic background and educational skills. Besides my growing commitment to alternative educational models--expressed through my work since 1978 as a core faculty for Union Graduate School and my more recent connections to the University Without Walls--I've been involved in the development of educational programs around disability.

In 1975 I co-founded, directed, and taught in a joint CIL/Antioch M.A. program in counseling persons with physical disabilities. Unfortunately when Antioch took over the entire program in 1977, they failed to publicize and develop it and could not even increase the original enrollment pool. A few years later in 1980, I created a Ph.D. program in health psychology at the Wright Institute in Berkeley. The school, however, in a paroxysm of conservative reorganization, removed its president and most of the more innovative administrators. The school then decided not to offer a specialization in health psychology. Nevertheless, I managed to raise enough money in the two years the program existed to get full scholarships for a couple of severely disabled students. Despite the administrative maneuvers, general incompetence, and negative attitudes toward disabled persons I lived with in these aborted academic enterprises, I obtained invaluable knowledge and experience as an academic administrator and as a teacher--as well as a greater cynicism and caution about academic institutions. Nevertheless, I'm convinced that education will improve the social role of disabled people, and I'm not yet too discouraged to explore other means of attaining this goal.

During this time I continued with my own education and learning. The most significant part of this were my visits--with Megan--to Milton H. Erickson, M.D., in 1977 and again in 1978. He taught me an incredible amount about both the substance and quality of hypnosis, therapy, education, and disability. The most important aspect of my learning from him as an appreciation of his wit, insight, intelligence, in short, his humanness.

In the midst of all this exciting and occasionally confusing and disappointing professional activity at CIL, Antioch, and the Wright Institute, a major event occurred which has had enormous effects on my personal and professional efforts. In 1978 my son Noah was born. His prematurity was caused by mistakes made by medical staff. Besides the often unnecessary fear Megan and I both felt, their errors also resulted in Noah being in intensive care for a week and produced many months of frightening medical and genetic possibilities. When he was nine months old, Noah had open-heart surgery. It seems that his particular heart defect is corrected, but the possibility of additional surgery won't be eliminated for many years. As difficult and scary as this time was, my greatest comfort came from Noah--just being with him and feeling his toughness, his warmth, his intelligence, and his humor.

I hope I've learned enough from all this to be able to work closely with other fathers--especially men who need to deal with disabled, at-risk, or potentially disabled infants and toddlers. It is precisely on this topic that I feel a strong desire to learn about infant/toddler development, father/child bonding, and about parenting issues in general.

This interest, combined with my past skills and training around adult disability, will enable me to offer invaluable and unique educational and counseling services to both physically disabled fathers and to men with disabled or at-risk infants or toddlers.

Regional Oral History Office
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University of California
Berkeley, California

Disability Rights and Independent Living Movement Oral History Series

BUILDERS AND SUSTAINERS OF THE INDEPENDENT LIVING MOVEMENT IN BERKELEY
VOLUME IV

Michael Pachovas

BERKELEY POLITICAL ACTIVIST, FOUNDER OF THE DISABLED PRISONERS' PROGRAM

An Interview Conducted by
Mary Lou Breslin
in 1998

TABLE OF CONTENTS--Michael Pachovas

INTERVIEW HISTORY	194
I BACKGROUND, INJURY, AND REHABILITATION	196
Early Years in Gary, Indiana: A Working Family	196
Ethnic and Racial Politics in Gary	200
Vietnam War Draft Deferment	202
Joining the Peace Corps, 1969	205
Peace Corps Orientation and Assignment in Ethiopia	208
Breaking Neck in Diving Accident in Ethiopia, 1969	213
Evacuation to Germany	219
Hospital Experiences in Wiesbaden, Germany	222
Rehabilitation in Chicago, 1969-1971: Fighting the Medical Regime	227
II EXPERIENCES AS UC STUDENT AND ACTIVIST IN THE DISABILITY RIGHTS MOVEMENT	232
Return to Family Home	232
First Organized Consciousness of Disability Rights: The National Paraplegic Foundation	234
Family's Reactions to Disability	235
Move to California to Attend UC Berkeley, 1972	237
Impressions of the Disabled Students' Program	241
Recalling the Cowell Residence Program and Rehab Counselors	248
Relationship with Ed Roberts, Assessment of His Leadership of DR and CIL	253
Life as a Student; Disabled Prisoners' Program, and Sex Therapist	257
The Best Radical Teachers	257
Campus Access Survey	259
Disabled Prisoners' Program in Vacaville	260
Training as a Socio-sexual Counselor/Educator	265
California School of Professional Psychology	265
Rivalries, Leadership Styles, Institutional Survival, and Stumbling Blocks	267
Rivalry Within the Disabled Community	267
Cult of Personality	269
Negative Impact of Growth	269
Shift in Priorities	271
Original Issues No Longer Addressed	274
III TWENTY-SIX YEARS OF POLITICAL ACTIVISM AND THOUGHTS ON FUTURE CHALLENGES	279
Chained to a Rock for Ten Days, Saving Wild and Scenic Rivers, 1981	279
Stanislaus Wilderness Action Committee	281
Public Relations Vigil	282
Response from the White House	285
Victorious End to Vigil	288
Disabled American Freedom Rally, 1981	290

193a

Common Ground Issues	292
Complex Strategy for Public Support	293
Caravan and Support Network	296
Fear in Washington and FBI Infiltrator	299
Demonstration in Washington	302
Stoned on Hash Cookies	304
Impact of Freedom Rally	306
Disability and Broader Issues	308
Impact of the Disability Rights Movement and the Momentum from Berkeley	310
Remaining Challenges: A Declining Economy and Developing New Leadership	314
Towards a Disabled Emergency Services Program	318

INTERVIEW HISTORY--Michael Pachovas

Michael Pachovas was interviewed for the Disability Rights and Independent Living Movement Oral History Series because of his role as a disabled student activist at UC Berkeley in the early 1970s and later as an advocate in the disability, environmental, and social justice movements in the San Francisco Bay Area and nationally. He contributed to the founding of several disability programs in the Bay Area including BORG (Bay Area Outreach Recreation Program) and the former Disabled Prisoners Program. He offers keen observations of the leading disability organizations of the Bay Area.

Mr. Pachovas broke his neck in a diving accident in 1969 after having served only one month as a Peace Corps volunteer in Ethiopia. After spending two years in the Rehabilitation Institute in Chicago, Illinois, he returned to his parents' home in Gary, Indiana. Faced with few employment options, little accessibility, and winter snowstorms, he decided to go to college in a warm climate. He made his way to UC Berkeley in 1972. Though initially unaware that there was a program for students with disabilities on campus, he soon became involved in university issues relating to disability. Like many people with disabilities, Mr. Pachovas did not at first identify with others with disabilities and did not perceive disability in a political or social justice context. His interview reveals a dramatic shift in these attitudes as he became involved in campus and community politics.

Mr. Pachovas was also involved in fostering the development of programs that challenged stereotypes and opened new opportunities for people with disabilities including participatory theater and a teaching and training program on disability and sexuality. He led a cross-country caravan of people with disabilities to commemorate the 1981 International Year of Disabled Persons and to draw media attention to proposed federal cutbacks in disability programs. Mr. Pachovas has continued to advocate for the rights of people with disabilities through service on various boards and commissions, and in City of Berkeley politics.

Mr. Pachovas's interview took place in three sessions beginning in July, 1998, and ending in September, 1998. Interviews, conducted in his home in Berkeley, California, were occasionally interrupted by telephone calls--frequently from prospective personal assistants--and by the charming demands of his two beloved pet macaws who would often climb onto the wheelchair armrests, handlebars, and shoulders of both interviewer and interviewee. Except for periods during the 1980s, which were less vividly recalled, Mr. Pachovas spoke easily and with very good recall. The interviewer was an acquaintance of Mr. Pachovas. The interviews were transcribed by the Regional Oral History Office and lightly edited by project editor Sharon Bonney. Mr. Pachovas was sent the transcript for his

review, but did not choose to make any changes. Copies of the interview tapes are available for listening in The Bancroft Library.

The Regional Oral History Office was established in 1954 to augment through tape-recorded memoirs the Library's materials on the history of California and the West. Copies of all interviews are available for research use in The Bancroft Library and in the UCLA Department of Special Collections. The office is under the direction of Willa K. Baum, Division Head, and the administrative direction of Charles B. Faulhaber, James D. Hart Director of The Bancroft Library, University of California, Berkeley.

Mary Lou Breslin, Interviewer

November, 1999
Regional Oral History Office
The Bancroft Library
University of California, Berkeley

INTERVIEW WITH MICHAEL PACHOVAS

I BACKGROUND, INJURY, AND REHABILITATION

[Interview 1: July 7, 1998] ##¹

Early Years in Gary, Indiana: A Working Family

Breslin: This is Mary Lou Breslin interviewing Michael Pachovas at his home. Hi.

Pachovas: Hi.

Breslin: We're really happy you agreed to be interviewed. I'm looking forward to hearing what you have to say. Let's just start with your family. Where were you born?

Pachovas: I was born in Gary, Indiana, in 1948. My twin brother and I were the eldest of seven children.

Breslin: Tell me a little bit about your parents.

Pachovas: They were both working class people. They were both above average in intelligence. What else about them--they were both Greek. They had been born here, first generation. My family all the way back is Greek and there was a lot of that. When I was growing up my grandfather lived with us and they often used Greek as a secret language, so they weren't real encouraging of us to learn it, although we learned what we needed to learn as kids to figure out what they were up to.

We were a very rowdy family. I think that just developmentally what I got out of that experience was learning how to be in positions of having all of the responsibility and none of the authority to do anything because being an older child I was responsible for all the bad things that any of the

¹## This symbol indicates that a tape or tape segment has begun or ended. A guide to the tapes follows the transcript.

younger ones did and yet I had no power other than threat to curtail their activities.

Breslin: Were threats successful?

Pachovas: Yes, I mean to hear them talk about it in my older age I think it was. They were somewhat afraid to get on my bad side.

Breslin: You have three brothers and three sisters, is that right?

Pachovas: I do.

Breslin: And they are all younger.

Pachovas: All younger, except my twin brother.

Breslin: And how far apart are you all in age?

Pachovas: Ten years.

Breslin: So your youngest sibling is ten years younger than you are?

Pachovas: Yes, she'll be forty in November.

Breslin: And you've recently had a family reunion?

Pachovas: No, my family came up to visit. My sister came out and my niece and my brother-in-law. And so that was the first time I'd seen them in about six years.

Breslin: Oh, that's great. Tell me about growing up in Gary, Indiana.

Pachovas: It was a tough town. We had a dry-cleaning plant and my mom and dad both worked, and as early as I can remember I worked. My first early recall was learning to tie a one-bow knot when I was about three years old so that I could help tie bundles of people's clothes, you know, when we would go out on the dry-cleaning route. And so every summer, we would go out when I was out of school and before I went to school. And I worked.

As a matter of fact, when I first went to kindergarten--I remember the first day I went to school it was a shock to me. I didn't want to go to a school; I was having a good time working, I liked it. I thought my life was about to change and I was going to have to sit in one place for a long time--this was age six--yes, five or six; it was kindergarten. I cried. I didn't want to be there, but they left me there anyway.

Growing up, both our dry-cleaning plant and the place where we lived were in a very mixed neighborhood. Gradually it became all black. And I ended up going to summer school a couple of years as the only white student in a black high school. That was kind of interesting.

Breslin: And which high school did you go to?

Pachovas: I went to Froebel High School for summer school. Froeble was the school right across the street from my dad's dry-cleaning plant. We were the only remaining white business there until my dad eventually went out of business and sold the laundromat and got into coin operated equipment. So most of my life I grew up in a dry-cleaning plant and spent most of my free time there.

Let's see, my first paid job was sweeping up when I was twelve. I got a quarter an hour for sweeping the plant and mopping the plant and I found out later that he fired the guy he was paying a dollar an hour to do the same thing for him. And then I never did see the damn checks, for some reason. I guess we must have been on hard times during that period. But after he wrote me the check for working all summer, it disappeared. I didn't know at that point that he could just write another check, so I just thought I'd lost my money.

Breslin: Oh.

Pachovas: So Dad was very good at exploiting us, and exploiting child labor. I think this is part of the whole ethnic thing--you work. You know, you just work. They don't treat children much differently than they treat adults. If you can work, you do what you can. That goes toward making everything run smoothly. I think that has some effect on what I chose to do in life in doing community service and not feeling like, gee, somebody owes me a big paycheck at the end of it.

I think that basically I learned good values from them. My mom was just born at the wrong time. She should have been running one of the Fortune 500 companies. She was brilliant. And instead, that's not what you did. She never got anything but an A in school in her whole life, but her mother forbade her from taking her scholarship and going on to college, because that's not what Greek women do and so she ended up marrying my dad and, you know, basically running the business.

Breslin: Did she work in the plant?

Pachovas: All the time. Yes, we were a working family.

Mostly we grew up as children with maids during the week. We had a live-in maid, so I learned a lot about southern cooking and ethnic stuff. You know, they were pretty much our surrogate parents. You know, Mom would say, "Yes, you know, if they need it, beat them. Sometimes they need it, so go ahead, it's okay with us." [laughs] "Wield a big stick, that's all right." So they kept us in line and then they taught us to respect them and all those things. What ended up was that we ended up not being a racist family at all.

We were well respected in the community. You know, my mom and dad gave everybody a break. And my dad had better business ethics than personal ethics, I think, and my mother was just a straight shooter all the way around. I think that between the two of them, it was probably my mom who gave us any sense of self that we had, as far as being a worthwhile person. She really believed in us, and Dad tended not to.

Breslin: What do you mean better business ethics than personal ethics?

Pachovas: Well, I never saw him take unfair advantage of anyone in a business deal in my whole life, but I didn't like the way he treated my mother. So in that sense, you know, I think that I saw mixed signals. My dad was an alcoholic and as his alcoholism progressed, his behavior became more erratic and I lost a lot of respect for him when he started quite a bit about things like that. Basically a good guy, but I think he didn't like women much, is what I really think in my older age. He didn't know how to treat them with respect and I didn't like that.

I think a lot of what I got was things from liking the way my mother acted toward people. Everybody said, "Oh, we go see Miss Flo, because she's real straight, you know. She's fair." Everybody loved my mom.

They liked my dad, too. You know, like I said, he treated people very fairly. And he always taught us not to take advantage of people in a business situation, and you know the basic stuff about the customer being right and all that other stuff. Eating it in the small run for greater gain down the road because it just made better business sense to do that. So I learned to make notes of things I needed to do if I wanted to get any of them done. So a lot of my time, even later in my life, was taking notes and making lists of what had to be done every day and actually trying to do them and check them all off.

Breslin: That carried forward in your career? [laughs]

Pachovas: Well, I like to think it did. But I more carry my notes in my brain.

Ethnic and Racial Politics in Gary

Breslin: You said that your community moved from being, what, multi-cultural or primarily Caucasian?

Pachovas: Yes, well, the whole city did. The whole city did. Now, I moved--we moved from an area of Gary called Brunswick. I was first born in an area called Tollison. Then moved to Brunswick and then moved to Miller. With each move it was kind of a little half-step up socio-economically, especially the last move up to Miller. Miller was like an all-white subsection of Gary, so it was kind of odd going to a white high school for most of the year and then going to a black high school during summer school sometimes. They weren't mixed.

Breslin: How did that happen? Did you go to different schools in the summer?

Pachovas: Well, yes, because when I went to school--I only went to Froebel for summer school--but during the regular school year then I went to different schools. I went to about four or five different schools in Gary because we moved and because some of the school systems only went up to certain grades. So first I went to Edison High School. When I was in kindergarten, for example; then we moved out to Miller, so I went to [Etna?] Elementary School and then Nobel Elementary School; and then [Worth?] High School for my junior and senior high school stuff. And then between my sophomore and junior year we moved out of Gary altogether and moved to Crown Point, Indiana. And that's when white flight kind of happened in Gary.

The first political thing I ever worked on was getting Mayor Hatcher elected in 1966. But when he came in, there were hard times in the mill and the town really was a company town, and if U.S. Steel was having hard times, everybody was having hard times. U.S. Steel decided they were going to close the plant down. Mayor Hatcher didn't inspire any kind of confidence in the white business community in Gary and so they decided to pick up their marbles and move south and most of

them settled in Maryville which was just south of Gary and then to other parts of the county.

But there was a massive migration and housing prices were almost instantly depressed. Houses that you would buy for, you know, \$40,000-50,000 you'd be lucky if you could get \$16,000 for right after he became mayor.

He came and purged the old administration in Gary instead of working his own folks in. And that purge scared everybody because they were used to dealing with a certain number of people that they knew in city government. Now this was a whole new group of people that they didn't know. Ethnic politics and then racial politics in Gary were very intense during that period of time. Gary had gone about 60 percent black to white and--

Breslin: This was the sixties?

Pachovas: Yes, 1966.

Breslin: You know, Gary was the site of very serious race riots in the mid-sixties. Did they affect you?

Pachovas: No, not really, because there were so many other things happening at the same time. For an example, in '68 there was the Democratic convention in Chicago. Gary is practically a suburb of Chicago because you just swing right up the lake and you're there. The race riots pretty much went past me. As I said, you know, our business was one of the last white businesses in downtown Gary that remained open. We never had any of those problems.

Now, there were episodes when I was going to a predominantly black high school and black people not liking that I was going to school there and wanting to go fight or something else. I tried to learn how to get along.

Breslin: This was because there were so few white students, generally, or was it about you in particular?

Pachovas: No, it was because I was the only white student.

Breslin: How was that for you?

Pachovas: Easy academically, and because I'd been used to growing up there, it wasn't that hard. You know, I didn't think about it in terms of race that much unless there was some obvious incident where somebody would say something racial.

Vietnam War Draft Deferment

Breslin: This was also the period when the Vietnam War was heating up in terms of protests, well, all over the country, but certainly around the Chicago area. Did that affect you at all? Did you have any role in any of those?

Pachovas: I didn't want to go to Vietnam and get shot. I knew that. And thinking back on it, basically, I was a middle-of-the-road liberal Democrat. I didn't have any sense that if I got drafted I was going to go resist. I mean, I don't think at that time that would have entered my mind that that's something that one should do, because I knew I wouldn't have wanted to carry whatever stigma that might have had throughout life.

I did get called by the draft board, and [laughs] I went to my draft induction physical. I was a really big guy so I thought, well, they're not going to take me because I'm just too big. It was kind of a whole funny story, but they did take me to Chicago up to Randolph Station and I got on the bus. We stopped in the harbor and picked up a lot of folks from the Latin community, including one guy that had one leg. I just was astounded that here was this guy going to take this draft induction physical who only had one leg! And all of a sudden my prospects of getting out of the draft started to diminish rapidly.

I asked the guy, who didn't speak a lot of English, "Don't they know you have one leg?" He said, "Yes, they said go take the physical." He had this prosthesis with him and he wasn't sure whether he should take it and show it to them or carry it, but he decided he should carry it so they really understood he had no leg. And [laughs] we went to the draft physical. When we went in there together he hopped up the steps and carried his prosthesis with him. Nobody batted an eye, nobody thought that was odd--except for me--I think. No one even questioned him.

We sat down. We took the test. The man didn't read or write English so he just kind of stared at the test; I did my mechanical aptitude and all that kind of stuff, and then we went to do the physical part of it. We all had to go down to our skivvies and go stand in lines. Still nobody was saying anything to this guy. I thought, "Oh my god. You know, doesn't anybody here think this is odd? You know, are they going to take this guy into the army?" For sure I knew I was going if they were going to take this guy.

But finally we got up to get weighed and some doctor walked up to him and said, "What are you doing here?" He said, "They're telling me I got to take the physical." He said, "Didn't they see you have one leg?" He says, "I tell them I have one leg, they say you've got to take the physical." So he said, "Get out of line and go there."

Now, whenever they told you at the draft physical get out of line, you took that as a very positive thing.

Breslin: That's good news.

Pachovas: So I was thinking, "Oh. good, they're going to do that to me, too. I'm going to get up there and the scale's going to go around and they're going to say get out of line." I got up there and the scale went around and they said, "Get off the scale, please," and that was about right. And then they just adjusted the scale to make sure it was reading right. I got back on the scale and they said, "You don't weigh that much!" I said, "I swear I do. I weigh that much." They said, "Well, okay, step out of line." And I thought, "Oh, great."

Breslin: Me, too.

Pachovas: Yes, "Me, too; me, too. I don't want to go. I don't want to get shot, I don't want to shoot at anybody I don't know." I thought the whole thing was stupid.

They took my--they did a battery of tests--and they said, "Oh, no, you're real healthy." I said, "Well, what about my weight?" They said, "Oh, we can run that off you." And I thought, "Oh, this is just what I want to hear."

Now, for me, I was very active physically, very active in high school. I was a jock and got more into the individual sports than I did team sports. I was my high school boxing champion and the handball champion of the school. And we had an open tournament where the faculty could meet in handball. I played a bunch of sports. I was really good on the trampoline even though I was huge. On the weekends, I had had a wonderful coach in high school named Russ Keller who taught me a lot about community service and really turned my head around from kind of being somewhat thuggish, you know, as I grew older, to being more civil. In Gary what I learned was, you know, you either had to be bad, or you had to be fast, or you had to have a good rap.

Breslin: Or all?

Pachovas: Or all, yes. All of them were helpful. I wasn't fast. I was coordinated, but I wasn't fast. And for me, you know, if I had to go more than a quarter of a mile, I'd rather take the bus. I wasn't into long runs. But this guy, Russ Keller in Crown Point, started a school for children who were younger in the community who didn't have access to gymnastics apparatus. He talked to a bunch of us who were P.E. instructors at the time and he said, "You want to help me with this tumbling class on weekends?" So we all did. I think that and Boy Scouts and all that really taught me a lot about being civic-minded and giving of your time to the community, besides money. I wasn't getting any money working for my dad, so I might as well do something that was fun. And so I did that for a while.

Breslin: I take it you didn't identify as a hippie in those days.

Pachovas: Not at all, no. That didn't happen until during my rehab experience. It still didn't feel like I was a hippie, but I sure learned a lot about not blindly following instructions and orders. Up until nearly the point when I broke my neck I'd say that I was just your average liberal.

I joined the Peace Corps out of college.

Breslin: Well, what happened with the draft board?

Pachovas: Oh! So I got out of line. They took my things and they told me that they could run that off me. So all of a sudden my prospects sank again of not having to pick up a gun and shoot at somebody and ducking bullets and all that. You know, I was resolved, if my number got pulled in the lottery. So if I had to go, I had to go. Although, you know, like I said, I didn't want to.

What happened was I got to this point where they ask you to squat down and then jump up in the air. Well, I had just had knee surgery from a knee that I'd blown out earlier doing some sports and so I couldn't jump up in the air because my knee was still healing. I didn't think anything of it, but they said get out of line, and again, my spirits soared. So I got out of line and they came by and they checked all of us who had like fallen out, weren't part of the herd. And the doctor said, "What happened?" I said, "Well, I blew out my knee and I just had surgery on my knee." He said, "Give me your paperwork," and he stamped 1-Y on it and I went, "Oh my god, I'm not going to Vietnam. That's very cool." I didn't even know that was some legitimate reason for getting out of the draft, but it got me a pass, basically. You know, 1-Y deferment was you had to

check in with them once a year to see if your condition improved and if it didn't, you know, you went back to school.

That was during a time when mostly the draft was taking minorities in my area of the world. Now, I don't know how much messing around with the lottery numbers and stuff that the local people did, but my sense from looking at the population on the bus was that rich people's kids weren't on the bus. But who was on the bus were dropouts from college, even if temporary, because you know we used to have a 2-S deferment when we were in college. Well, that was the year that I'd gotten in a motorcycle accident and had to drop out a quarter to take care of my leg. As soon as I was out, my number got called. So I think that was more than coincidental. They were looking for officer material, young officer material, so I think they were doing a pretty good purge of those kinds of rules, to make sure that if you dropped out of school, they called you up. And minorities. They had predominantly minorities--just an overwhelming proportion of minorities were being inducted at that time.

Breslin: Did you go directly from high school to college?

Pachovas: Yes.

Breslin: And where did you go to college?

Pachovas: Indiana University in Gary. I was a lit major. I was in the advanced expository literature program because I got decent--what are those called--College Board tests, SATs, something--and I figured out I could write.

Joining the Peace Corps, 1969

Breslin: What did you think you were going to be? What was your career vision at that time in your life?

Pachovas: You know, I wasn't sure. I wasn't sure. At one point I thought I was just going to go be a professional football player. Growing up in high school and all that, that's what I was going to do; I was going to be a pro football player, then go be a coach. But then when I blew out my knee, that changed a lot of that. And so at that time, I knew that I wanted to write and so one of the things I liked about going into the Peace Corps was that it would give me good material to write about, especially going to Africa.

Breslin: Why did you decide to join the Peace Corps?

Pachovas: I don't remember. I think there was a combination of a number of things. I was past having to go into the army, I knew I didn't have to do that. I did have a strong sense of service, you know, of wanting to serve the government, of wanting to serve our--not the government so much, but our country--and some way that was productive and it sounded romantic to me. I don't know what the specific incident was, but I think in retrospect it probably was that I wanted to get away from home, I wanted to do something that I thought was rewarding, and it seemed like a time just to take off and see who I was.

Breslin: So when did you join the Peace Corps?

Pachovas: In 1969.

Breslin: Tell me about that.

Pachovas: I made the application to the Peace Corps and I was surprised to have people come out and tell me I was even in the running because I was, you know, just twenty years old at the time. Generally you had to have a degree at that time, you had to be older to get in. But they needed people who were talented with their hands, and growing up and working in my dad's business and then into the dry-cleaning business--excuse me a minute, I'm going to--[tape interruption]

Ah, they tapped me because I was skilled with my hands. I could build things. The previous summer I had worked for the county road crew, building roads and repairing roads. Before that I'd literally built laundromats from the ground up and dry-cleaning plants, so I knew masonry, I could lay pipelines. That turned out to be the primary skill they wanted me for, to drill wells so that we could bring water for the people who were trying to grow food. So I got a letter saying, "Gee, would you like to go to Ethiopia?" So I went on a map to see where Ethiopia was and I realized, oh, that's in Africa, that's in east Africa, it's near Kenya, that sounds good. Okay, sure, I'd like to do that. Generally--

Breslin: I didn't mean to interrupt you, but I was wondering if you had any idea what life in Ethiopia was like at that time?

Pachovas: None, not a clue, but I figured if the Peace Corps was sending you there, it couldn't be all that good. So they weren't sending us like to the Bahamas, or anywhere fun.

Now, that year also was significant because I'd lost several friends in Vietnam and the whole full impact of what was going on back then had come to roost. We'd just had the riots in Chicago and they were going on there with the Democratic convention. I was just hauling laundry machines back and forth while most of that was going on and was somewhat oblivious to what was going on.

When I was on campus at that time I was a member of the Circle K, which was like the college Kiwanis Club, so we did a lot of social things for the college. And yet there was an SDS [Students for a Democratic Society] chapter that was starting there who were mostly a bunch of real jerks. I didn't relate to anything that they were saying because of the way they were going about doing things. I just disagreed with people just being jerks for no sensible reasons. So I never understood what the message was at the time that they were trying to get out, other than they didn't want to go to Vietnam either, and they thought the war was wrong. I certainly agreed with that, although the way I felt about my relationship to the war and what they were saying was not the same. It was also the Young Democrats at the time.

Breslin: What were the differences between SDS's view from yours about the war?

Pachovas: Mostly tactical. For me, as I said before, if I'd been drafted, I would have gone. They were, at that time, rioting. You know, they were disrupting classes and they were disrupting lectures and things. It was somewhat of a clash for us because we were there being ushers, so there was this natural clash where we're supposed to be helping people find their seats and then they're there to disrupt the place. We were kind of caught in the middle of it and so it was sort of annoying. As I said, the specific people--and it wasn't a really large group at Indiana University in Gary--but the specific people who were doing it were kind of morons, you know, and saw it as morons. This is an obnoxious group of folks who had gotten together who are malcontents. I had no idea what their point was at that time.

It wasn't until later, you know, really until later when I started meeting leftist leaning people even in the Peace Corps that I started to understand more about what was going on on the left. As far as I knew, if you were a Democrat, you're on the left, living in Indiana. I did a lot of student-organized Democrat things during those days, so our focus was much more narrow and the parameters in which we looked at the world were

much more narrow than what was offered to us as one of the whole plateful of alternatives.

Breslin: Were you philosophically opposed to the war, do you think, at that time?

Pachovas: Gee, I'd like to give myself credit to be. I thought that it was--I thought at that time that war was wrong--that war was a failure of foreign policy. That hasn't changed. I thought it was wrong to throw children into wars because you didn't get along with their government. I had no idea what we were doing in Vietnam. I also knew that my friends were being killed without any good reason that I could think of. Part of my resistance to that was I don't want to go somewhere where I have to shoot at people who I don't know. I don't want to go somewhere where they're shooting at me, even though the shooting at me part was less in my brains than having to go pick up a gun and shoot at people. That I found very objectionable. I wasn't raised that way. You don't go do that. But as far as being philosophically opposed to the war in Vietnam, I'd have to say no, because I didn't know to be. I just didn't like what was going on and I would have been opposed to any war at any place in time that was taking the lives of my friends.

Peace Corps Orientation and Assignment in Ethiopia

Breslin: Let's go back to the Peace Corps. What happened first?

##

Breslin: Okay. Back to the Peace Corps.

Pachovas: I got a letter that said that they wanted me to go to Ethiopia, wanted to know if I would accept a position there. I'd checked some boxes earlier and I had indicated that Ethiopia was one of those places that seemed interesting to me, or at least that part of Africa.

I think they gave me a choice of continents and I chose Southeast Asia and Africa and maybe the Mediterranean area as places that would be of most interest for me to go, and maybe South America, actually. So when this came up, I thought that it was interesting.

What was unusual about it was they weren't going to do things in this project the way had done with other projects. Generally when you join the Peace Corps you stay in the United States and you take language-immersion classes for something like--I don't know--four months or something and learn about the culture and a lot of other things, and then they send you to the country. But for us, they'd condensed that into about a week and a half and decided that they weren't going to teach us that. They wanted people who had practical skills and they needed them right now to go to Ethiopia.

So they got a group of nurses and a group of people that they perceived to be able to be rural development workers and who had the choice that they wanted, which as they explained to me was basically that you could independently work; you could figure out what needed to be done and do it. I had mechanical skills in my case. For example, they loved that I knew how to thread pipe and lay pipeline, and that I could drill a well. In other words, I could do things like build a road. Those were very desirable things. And I guess I had whatever level of intelligence they thought would be needed to do it.

I was somewhat surprised that they took me at nineteen years old. When I went to Philadelphia there were about 380 people that showed up for the job, of whom they sent over, I think, fifty-six. And in those two groups of nurses and rural development workers--

Breslin: All to go to Ethiopia?

Pachovas: Yes, they just sent the rest back home. So they took the fifty-six people they wanted. During that time we went through psychological screening and medical screening and all this other stuff. I was rather surprised that I was one of the ones chosen, but it kind of worked out that way because I liked having fun and people around me recognized I liked having fun and knew how to do it, so we ended up having lots of parties in my room. And as the group got smaller, we got closer together and more tightly knit so at the end of the week--at the end of the month when we were there--we basically were doing things as a group. All fifty-six of us would go to a bar or fifty-six of us would go to a hockey game.

Breslin: Now that's a vision.

Pachovas: Oh, it was really amazing. It was quite amazing at the time. I heard a rumor that they were thinking about not sending me because I may project too youthful an image.

Breslin: Does that mean you had too many parties?

Pachovas: I guess. Well, it's just that I was so young. Everybody in the group was in their mid-twenties or older. But they also thought, "Well, yes, but this guy was like the social director for the group. We can't very well not send him because that would be somewhat disruptive to the cohesiveness that they're showing." So there was some kind of negotiating done. But I do remember going to one of the meetings after that with a lollipop, just as a reaction against it. But they all had a good sense of humor and I really liked the people that they chose.

The people that they chose were just a cut above. I appreciated that. While I was at home in Crown Point, my friends would say, "Why do you speak in big words?" and this was a clearly different environment. All the people I was with really had their act together intellectually as well as socially, and socially to a much greater degree than I did. They had a much greater social conscience and a consciousness politically and otherwise of events that I barely knew anything other than what I read in the Gary Post Tribune about.

It was very interesting. One of the people that went with us was a guy named Harold. We called him old, weird Harold. Harold had been a major in Vietnam at about, I don't know, thirty years old or something and then finished his hitch and joined the Peace Corps. And at that time the Peace Corps certainly had more problems than my youthful demeanor because we were dealing with CIA infiltration of the Peace Corps. Of the huge perception that everyone in the Peace Corps was a potential CIA agent. Specific to our group--we were succeeding a group of teachers who went over there and displaced Ethiopian teachers and would be teaching Ethiopian history--things like that, so it wasn't making any sense. And they were boorish; they would be loud and obnoxious and get drunk and create problems in the community and weren't very respected.

That might have had something to do with why the government decided they wanted to get another group over there that could change that situation around because the teachers weren't cutting it as a group or as a project. The Ethiopians weren't embracing them by any means. My experience when we got there was that they loved having us be there, they loved having us working next to them, picking up shovels and doing practical things. We weren't displacing their jobs.

We did tend to have this sort of cultural imperialism that I picked up on really fast, but we thought that--and it was

almost unconscious--was largely unconscious, that what we were doing and the way we did it was more significant and more important than the way they had been doing it. We tended to look at their culture as if it were somewhat charming and naive and unsophisticated. But if you would really scratch the surface of that and try to get into the roots of it, you'd find quite an evolved social and cultural progression of events that led to why things are the way they are right now.

Also, it was incredibly chaotic and disorganized as far as the way the government worked over there. We had, for example, in the village that I was in--they had sent--oh, who was it that sent him? Oh, what is that big farm group? Oh, doggone it, it wasn't Oxfam America. There was a group and it's not in my brain right at the moment, that sends food and agricultural equipment into--

Breslin: One of the relief institutions, CARE, or something like that?

Pachovas: Yes, it wasn't CARE, but it was one of the others that is like that. One of--the big one. Well, they sent this village a tractor, you know, a John Deere tractor, I think a \$20,000 piece of equipment. And they built a shed and they kept it there and they kept it really shined up and it was beautiful, but nobody ever used it because you had to put gasoline in the tractor and a gallon of gasoline was roughly a year's wages in Ethiopia, so nobody ever used it. They didn't find it as practical.

Well, what we did was talk to some of our friends who were in the Peace Corps in Kenya and found an agricultural cooperative that was large going on down there and they could use the tractor. So we traded in the tractor for twenty oxen which was very practical for our folks, and it was totally illegal to do, because you had to sign all this paper work.

Plus, a lot of the food that was being sent to Africa at that time, no matter where it was, was being diverted into the army. They were having the revolution up in Eritrea at the time, and so food that would be going there was being diverted to get people to work in the army. If you'd join the army, they would feed you, and that was a big deal. I mean, we had starvation and poverty going on in Ethiopia long before they figured out that that stuff was going on.

Breslin: You joined the Peace Corps in 1969?

Pachovas: '69, yes.

- Breslin: And how long did it take you to actually get to Ethiopia?
- Pachovas: About two weeks.
- Breslin: So right, really no orientation.
- Pachovas: Yes, none.
- Breslin: And you were assigned to a village right away to begin working?
- Pachovas: Yes, yes.
- Breslin: Given what you've described about the country and the circumstances, did you think that the work you were assigned to do made sense?
- Pachovas: Oh, it did. Yes, but when they sent me over there to drill wells, they didn't tell me they didn't have any pipe. So yes and no. Yes, sure--
- Breslin: Good idea, bad planning.
- Pachovas: I was amused to see a commercial about four years ago about a rural development in Ethiopia. There was a well-driller and he had these huge stacks of pipe behind him. I said, "Yes, right."

What I learned to do was I learned how to patch bamboo together with tar paper and run water through these huge pieces of bamboo. So we helped each other a lot. We had a pump. You know, we could get the stuff into the ground and get it up, but from there we had no way of taking it anywhere other than to drill an irrigation series of ditches. But when we could splice bamboo onto the end of the pump and tar it all together, you could carry water greater distances.

Another friend of mine was working with some folks down there--with a nomadic group of folks--who every three or four years would experience all their houses being blown down. They used to be made of straw, but since World War II they'd been made of corrugated tin. But their houses would blow down because in the Blue Nile valley, the winds would come every three or four years and they would pack them all up and move to safer grounds.

Well, he thought they didn't have to do that if you'd just teach them to build an A-frame house, so he taught them to build an A-frame house. They loved it. They loved these A-frame houses.

And after I'd gotten hurt and gone back to Chicago, he wrote me a letter saying he'd gone back to the place where he'd taught these people to do this and was really dismayed that they'd just up and left the houses. He just was beside himself. He couldn't understand why. They didn't need to do that. I said, "Well, Corky, you just tried to change 5,000 years worth of habits and civilization here, and these folks have other reasons why they might want to move upstream. They certainly weren't going to stay there just because they had a new house." So there was a lot of that kind of stuff going on. You know, the silliness--

Breaking Neck in Diving Accident in Ethiopia, 1969

Breslin: Not very aware of the cultural issues of the places people were working. How long were you in Ethiopia before you got injured?

Pachovas: About three weeks.

Breslin: [laughs] Oh!

Pachovas: Yes, I got injured in my third week.

Breslin: Tell me what happened.

Pachovas: Well, let's see, what happened. It was kind of an interesting day. We'd gotten sent out to another village--I can't remember whether it was because we were going to be doing a short thing on language-immersion--there was some reason we got sent to this small village near this lake called Awasa. And the first day there the governor was throwing a big party for the Peace Corps workers. And so we'd all gotten there.

At that time I'd fallen in love with this one nurse and she'd missed the bus from Addis Ababa to this small village. You don't miss the bus in Ethiopia. It's not like being in Oakland and missing the bus. [laughs] You know, if you miss the bus in Africa, it's serious. So I was very worried about what was going on with her and what was going to happen to her, all this other stuff, and I almost missed the bus because she hadn't made it. So anyway, I'd thought about that all day and was wondering about what to do about getting her to this village. In the meantime, we had to show up at this event that the governor was throwing for us.

One of the things I didn't like about Ethiopia was the everybody drank warm beer. I can't stand drinking warm beer.

Breslin: Refrigeration's a problem. [laughter]

Pachovas: Yes, it was a problem. But you had to drink beer rather than eat the water or you know the fruit or anything. You had to have something. It's the first time I'd ever had bottled fuzzy, fizzy water and I thought that was kind of an interesting concept--or that they would even sell water in a bottle, which was even a bigger joke. But we did a lot of bottled water over there.

So the village that I was staying in, we were each assigned to a shack with an Ethiopian and I was with the language instructor for our village, a very nice man. Well, we all walked to make it--you'd go down--the directions were go down this road ten kilometers and turn right and go two kilometers and then come back three kilometers. And I thought, well, that's stupid, I'm just going to go down seven kilometers, turn right, and cut through the woods. Well, you don't cut through the woods in Africa. I found that out, once I got into the woods. As a matter of fact, I'd found out just after that when I got to the governor's mansion that one of our people had gotten mauled by a lion, and so they don't want people wandering off into the jungle.

I think I have this lucky sense of dead reckoning because I stumbled out of the jungle to realize that I was really lost for a minute. I stumbled right into the governor's back yard, so it was good dead reckoning but luck. I wasn't--I didn't want to drink--I was hot and I was concerned about my friend.

Then all of a sudden, about an hour into the party, she came up the road in this jeep full of Ethiopian soldiers who were drunk and firing their guns into the air and having a great time. I was pissed because I'd spent all this time worrying and she was having a good time.

And so at that point in time I was too mad to go and talk to her so I decided to walk back to the village. So I walked on back to the village. I was really hot and really sticky and needed to bathe, but our village didn't have any kind of bathing facilities past sundown, so that meant that if I wanted to bathe, I had to bathe in the lake. Another friend of mine from Philadelphia was there. Nearly everywhere where there were people, somebody has a bar in their house.

Breslin: Has a--

Pachovas: A bar in their house and so you go to your favorite house--

Breslin: A liquor bar?

Pachovas: Yes, a liquor bar. They have dirt floors and straw sides, but Chivas Regal and all these things on the shelves, you know. That's how they make their living.

So I needed to bathe--but I used to be a lifeguard at one time and I know you don't go bathing by yourself, you know. There was no moon. It was totally pitch black. And there was only one pier that went out into the water, [sigh] so I went to find anybody that might be around. He was, by that time, pretty shit-faced in a bar near the dock that I was going to go swimming from. So I asked him if he'd come out and hang out with me for a while and he said yes.

So he did and I remember we were talking for a long time--I was bouncing up and down--on this kind of makeshift diving board that we had. I had been swimming there before, so I knew the water to be deep. I remember trying to remember what kind of dive I should do because I liked diving. I remember I couldn't see the surface of the water, I couldn't see anything. I said, "Oh, I'll just do a jackknife and go into the water."

I did and wham! I hit my head on something really hard. And it broke my neck and I was just floating in this abyss underwater in pitch black and not able to move anything. I summed up the situation really quickly that I was in deep doo-doo.

I remember feeling rage at my situation. I was angry that this was my situation. I couldn't get anything to move and I was confused by not being able to move anything--didn't know what that was all about at the time--but knew that I better hold my breath as long as I could and hope that somebody figured out that there was something wrong.

Breslin: Were you oriented in the water at that point?

Pachovas: Not at all, it was just a black layer.

Breslin: You must have been incredibly disoriented.

Pachovas: Yes, I was. It was very disorienting. Although that wasn't the initial feeling that I had, because I didn't have time to think about it other than being angry, trying to figure what to do about it, realizing I couldn't do anything about it but hold my breath. I held my breath as long as I could and then

started drinking water. The last two things that I was conscious of was, "Damn, my mom is going to be really bummed out to find out that I died," and that my girlfriend was going to probably blame herself because we'd gotten into this kind of row before I left. I had no way of saying, "No, it's not your fault." And then I just went black.

Oh, you know what else happened--earlier that day--it's weird circumstances. I had this feeling I think of cultural--what do they call it--I want to say culture clash, but basically I felt like I was out of place. I needed something familiar, so I decided that morning that we were to leave for this village--I would go find the Greek church in town--Ethiopia is big on Orthodoxy.

So I got this weird ride with this guy who took me all over town. We got into a big argument, and then we found the church, which is about as big as this living room. I mean, it really was small. I'd gotten there and it was like early in the morning and it was a Sunday, and so I couldn't imagine why people weren't there.

There was a guy gardening out in the back, so I decided I'd go out and talk to him. I'd brought this bottle of booze with me that I was going to give to the local priest from Athens, when I was up in Athens on the way over, and so I talked to this guy and he turned out to be the archbishop of Africa and he was gardening in the back.

And he was very delighted to have someone that he could practice English with. And so we got into a really good discussion, I gave him this bottle of booze, and he invited me to stay for service and to come visit him and talk with him--in English, you know--at his home which was at the prince's palace.

I didn't realize that that was a big deal at the time. I said, "Okay, fine." So we went to church, went to services, did all that stuff, felt good about it, and then went on back. And my advisors had asked, you know, where I'd gone and I told them what had happened and he was just--Oh my god, it was like this international incident. I'd gotten invited to the prince's palace and no American had ever been invited to the prince's palace. And it was all this bottle of booze that I gave this guy, you know? And being happy that he had somebody to speak English to.

Breslin: What prompted you to offer that gift?

Pachovas: It was a--it's kind of what you do. It's kind of a social thing from being Greek. I wanted to get to know the local priest.

Breslin: But you brought that tradition with you from when you were--

Pachovas: Growing up, yes. The reason I mention that story was because I don't know if there's anything to religion or not and why I sought out a church that day. I don't know, because I don't do that and I've never done that again. I never did it before, but I did that morning. And when I woke up on the beach, I was so surprised. I've got to tell you, I was the most surprised person in the universe at that point in time that I wasn't dead. I remember lying on the beach and staring at the sky and seeing stars and going, "Wow, I'm not dead. How cool. There must be a god. There must be some reason to this." And, "Geez, I'm glad I went to church this morning."

Breslin: And a bottle of booze will buy you a lot! [laughs]

Pachovas: I'll tell you, I think it bought me some time! And I thought, "What is this all about?"

I don't know how much passing of time had happened, but at that point there were people around me who were medical people. And I guess this guy had dragged me to shore. Now, he was only about half my size and it was probably, geez, I'd have to guess, twenty yards to shore, so it was no easy feat that he got me back and revived me. So I was lying on the beach and I'm happy to be alive and I'm just thrilled. I couldn't move anything, but at that point I didn't really care. I mean, I'd come back from being dead. And it was the only time--and I've been in a bunch of jams in my life and I've gotten hurt a lot and done a lot of stupid things, you know, in athletics--but I never experienced what I thought to be my own death.

They were putting pins in me, saying, "Can you feel this? Can you feel this? Can you feel this?" I'd say. "No, no, no," or, "yes, yes, yes." Everybody was very concerned, except for me. And they were like having all these conversations until one of them said, "Do you want us to call your parents?" And that got my attention. I said, "Why do you want to call my parents?" They said, "Well, we think you broke your neck."

I had never heard of anybody breaking their neck and not being dead. You know, I've heard of horses, you know. You shoot horses and all that, but I've never known anybody to break their neck and not be dead. I'd only known two disabled people in my whole life up to that point.

I said, "Well, do you know for sure?" And they said no. I said, "Well, Jesus! Don't call my parents and tell them something like that!" Which they disobeyed and went and did anyway. At that point they figured that they had to get me out of there, but I was really in the middle of a jungle and it was about twenty kilometers to the closest thing that resembled medical care. Well, I was really lucky that here I was amidst a group of nurses and doctors who had come down to do this whole social event at the governor's mansion.

So a nurse and one of the doctors and some of the folks put me in the back of a Land Rover and bounced me through the jungle--which was very painful--to this Norwegian missionary hospital which was very small. I mean, it was about the size of this kitchen. It was a one-room house-like thing--shack-like thing--and they immediately took a hand-drill and drilled holes in my head and put Crutchfield Tongs in my head.

Breslin: They had them there?

Pachovas: Yes, it was amazing. They had them.

Breslin: Astonishing.

Pachovas: There was one doctor, one bed, and I was in it. They didn't even take me off the stretcher because they just were so sure I was going to die. And I--at that time--I had no doubts that I was going to live. Our realities were very different--it might have been the morphine--but I had no doubt, at that point in time, that for some reason God spared my life and I felt that very strongly at that time. Why, I don't know or, you know, why he bothered I didn't know. But he did. And so for me it was, "Okay, well, let's get past this. Let's get over it and get on with it." For them it was, "Geez, what do we do next?"

So I was there. They put these Crutchfield Tongs in, they put a catheter in, they had a nurse with me. And it was kind of weird kind of watching my urine run down the side and all that kind of stuff. I knew this was not a good thing, but I didn't know that it wasn't something that you couldn't just heal and get over. I knew nothing about it.

Evacuation to Germany

Pachovas: So they decided that they needed to try to get me to somewhere where they could do something for me. And the military was very helpful in this.

It may have been coincidence, but one of the things that happened on my flight from Rome to Addis Ababa the first time was that my girlfriend and I and this colonel from this military installation up in Asmoura happened to sit three abreast on the flight. It was a really long flight. Although we didn't have much in common, by the end of the flight we were pretty friendly with each other. You know, we were all just people and he kind of liked us. He was all right, you know? We had different attitudes about the war and stuff, but we were able to talk about them.

Well, a lot of military things happened at that point. They sent a helicopter into a clearing near this hospital and they got me and the bed--they just lifted up the bed and put it on a flatbed truck--and drove the truck out to the clearing and then transferred the bed onto the Healy helicopter.

Breslin: This was the U.S. Army?

Pachovas: Yes, this was all the United States Army. Then they flew me to Addis Ababa. I can't remember what kind of vehicle they took me to the hospital in from the helicopter, but I do remember how beautiful it was lying in the side of an open helicopter and flying up through the jungle and up through the mountains. It was just gorgeous.

As long as they kept giving me morphine I was okay. As I said, everybody else was more panicked about it than I was because my blood pressure was going all over the place--60/30 to 250/180 and all that kind of stuff. [laughs] I was a mess.

Breslin: You didn't know you were a mess.

Pachovas: I didn't know I was a mess, no. I didn't know how likely fatal that was at the time. I just knew that God had saved my life and so, "Okay, we're going to get on with it."

So they took me to this hospital and they took x-rays of my neck. The x-ray equipment wasn't very good, but they could determine that there was something going on in there that was real involved and they figured out that I had broken bones in there and all that stuff. I remember that a guy had come up to

me and said, "Look, this equipment isn't very good here. We need to really get you up to Asmoura at the military installation because they have a better hospital there." I said, "Well, okay. Let's do that." So they took me out and they rigged up this C-130 transport plane and they tied my bed to it and got me up there and then they flew me up to Asmoura. They took more x-rays. I guess the x-rays were very clear that I had broken my neck.

That's when I saw my friend the colonel, because he came back and he said, "Okay, look, here's what's going on. You've definitely broken your neck and we don't know much about that stuff here. I've got to be straight with you, I think that your life is very critical right now. And the two choices we have is we could try to fly you to Wiesbaden, Germany, where they can do something for you, or we can try to do something for you here. We don't think you'll make the trip."

Breslin: But you might not survive the local care, either.

Pachovas: Yes, but he said, "But we don't know much about it here." And so that was what I had to think about. They don't know much about it here, or I could try to get to Wiesbaden, which is another couple days away. I was just sure that I was going to live and so I said, "Well, I'm not worried about that, let's go on and get me somewhere where they can do something about this."

So he rigged up this C-141, I think, transport jet, a huge transport jet. They cut holes in the floor and they put foam down in there because they didn't want to take me off the stretcher, off the bed. They just didn't want to move me any more than they had to. They were very good about that.

Breslin: After you had been in a flatbed truck getting there to begin with.

Pachovas: Oh, I had been in a truck, in a bus, and in another kind of a truck, in a helicopter, and in another cargo plane. [laughs] So they turned me out.

He said he was going to fly the plane. Apparently he wasn't active in flying much then, he was just running the base, but he decided that he should fly. The problem was that I didn't have any identification, nothing, because that was still back in my shack in the jungle. So what he decided was they would have a helicopter fly back, grab my trunk, grab all my belongings, get my passport, fly that back to Addis Ababa, where they would have a fighter plane ready. They'd toss it in

the fighter plane, because the fighter plane could make it fast and direct to Wiesbaden without refueling because it could refuel in midair.

The cargo plane, however, had to stop and refuel in Turkey. That was not something I really wanted to hear. And he said, "Look, we're going to have to take you to Turkey and land. You don't have any ID, so we're going to put you in the back of the plane and we're going to put boxes all around you and when we hit the ground you're going to have to be real quiet." So I said, "Okay."

See, what was going on then was Cyprus was going on full--

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Pachovas: Well, so here I was facing the prospect of flying into Asmoura, Turkey--didn't like the notion much of having to be smuggled into Turkey--being that I was Greek and not having a passport and all that stuff. I don't know why we had to fly into a civilian airport, anyway, because it seemed like this was a military operation, so what's the deal? I mean, we've got bases up there.

For whatever reason, we had to stop in Asmoura, so they put me and a doctor and a Peace Corps nurse--and her name was Polk, Jane Polk, and she was an amputee, a BK amputee--in the back of this plane and they put boxes all around us and we had to just be quiet. Now, as long as they were giving me morphine I was doing okay. I would drift in and out. It wasn't of much concern to me, [though] I was pretty cognizant of what was going on around me.

When we touched down in Asmoura, we were all just told to be quiet. So we were all set in the back and then all of a sudden this Turkish face pops over the boxes! And his eyes got as big as saucers and he started screaming, "Assassin, assassin!" I thought, "Oh, man, this is not a good week." So I had these flashes of being thrown into a Turkish prison on top of all this crap.

The pilot--this colonel--came back and he told him that I was with the United States Embassy in Addis Ababa--because he demanded to see my passport, my papers, "What are we doing back there?"--all this other stuff. That I was from the United States embassy and I had a diplomatic pouch and I didn't have to show him jack shit for ID. That I had broken my neck and they were trying to get me to Frankfurt. Here was the flight order and if he delayed us and I died that it would cause an

international incident and the United States would cut off military aid to Turkey. It would be his fault. [laughter]

Breslin: That is not a bad explanation.

Pachovas: It was the best rap I had ever heard in my life! And the Turkish official took about ten seconds to think about this and then said, "Get out. Refuel. Get out." And so they did.

They refueled and actually the time warped there. It seemed like ten minutes but it was more like two hours. So they got me out of there and on my way to Wiesbaden. But the plane had to come into Frankfurt because it was so big.

Then they had sent a bus from Wiesbaden to Frankfurt to pick me up and they'd covered the back of the bus and opened the door real wide so it could accommodate a bed. So I touched down in Wiesbaden, and the guys who had driven the bus got tired of waiting because my plane was late so they turned around and drove back to Wiesbaden from Frankfurt.

My colonel was so upset that we came down, here I was, and there was no bus, no communications on the bus so they couldn't tell them, "No, wait, turn around and come back." [phone rings, tape interruption]

So they basically pulled me out of the airplane and just let me sit in my bed on the tarmac and wait for the truck to get back to Wiesbaden and then be told to turn around and go back to Frankfurt to pick me up.

Hospital Experiences in Wiesbaden, Germany

Pachovas: My mother and father were already there by then. They had called and they had told them. Everybody at home had a crying party because they didn't know what was going on. But the ironic part of it was that by then it was April Fool's Day and so people didn't know whether to believe I'd broken my neck or not. So half the folks thought this was some kind of prank and the others thought it was real.

My parents had to pay for their trip there. If you were in the military, you would have gone free, but in Peace Corps you had to pay your own. But they did clear all the paperwork and get them on the plane immediately and sent them out there.

My mother's recollection of it was that--oh, my mother was a basket case--by the time she got there. My mother was usually very sane and very stable. She was also very superstitious, although we never knew it. On the trip over there she had stopped by the mailbox on the way to the airport and in the mailbox was this crucifix that I had sent her from when I was in Rome and it just took a long time to get there. So she put this crucifix on, but somewhere during that flight she lost the crucifix from around her neck.

Breslin: Oh, no!

Pachovas: My stone from her mother's ring fell out, so she was just convinced that I was a dead man.

Breslin: Bad signs.

Pachovas: She was just totally convinced, so she told my father to go and see what was going on because she couldn't deal with it. And so Dad came over. She said, "You were just chattering away with him like nothing was wrong and having this very lucid conversation." I felt that I was lucid, you know. There would be a point when I would need more pain medication because you know, it was painful, but other than that I was fairly lucid. I had good conversations with everybody.

We had finally gotten the bus back, and needless to say these guys were dealt with militarily because they weren't supposed to have done that. They got me to Wiesbaden where they did surgery. It took about ten and a half hours. Mostly it was picking these bone fragments out of my spine.

So I had broken vertebrae three, four, five and six. And so smashed five that they couldn't save any of it, so they ended up putting a piece of my pelvis and some rib and making a block and doing the laminectomy and fusion in there. It was my great fortune that there was a patriot doctor there who had a very thriving mid-easterner--

Breslin: Mid-westerner?

Pachovas: No, in the east--he was in the Boston--

Breslin: Eastern U.S., okay--practice.

Pachovas: Yes, he had a very, very good neurological practice there. I think his name was Hall, but he was one of the pioneers of anterior fusion. Up until that point all the quads had

zipperneck stuff where they operated in the back and you could see a scar going down the back of your head and into your neck.

Breslin: They went in the front.

Pachovas: Yes, because they found out that that absolutely guaranteed paralysis. And if you could go through the front and just slit your throat there was a better chance of recovery from that kind of surgery. So they did that.

I awoke in this hospital and there were like three circle electric beds next to mine because I had--there was peripheral vision. Everybody was screaming.

It was like being in hell, because this was that maximum acute ward. What was happening was that Wiesbaden was being used as certainly the neuro-theater--the crisis center for Vietnam--for the guys that were medi-vacked out of Vietnam. They were sending them directly over to Wiesbaden and then directly over to Andrews Air Force Base in Washington and so they were there to ascertain whether or not they could survive the trip home.

It was not a good experience being in there. As I said, it was very military. People were screaming--and we had this nurse that was like a Nurse Ratchet--who was a major who was running the place. She kept threatening to bust people if they didn't stop screaming and, you know, toeing the line. She decided, for example, that I was overweight and should not get ice cream with my meals. Here I was dying and the only thing I had to look forward to, you know, was my ice cream. She decided I couldn't. So I complained and the doctors said, "What? Are you nuts? Give him his damned ice cream and leave him alone."

At one point I remember her saying to me, "No, you have to be a good patient, or I'll bust you." I said, "Hey, lady, you can't bust me, I'm a civilian." So that kind of stopped her cold, so she stopped being obnoxious to me.

My mom stayed. My dad, when he realized I was going to live, went back and, you know, had to go back to work, but my mom stayed the time I was there.

Now, about the fourth day that I was there, when they were turning me they forgot to buckle down the headboard, and although it had restraining straps when I went over, it came loose and it resnapped and it rebroke my neck. Up until that point in time I was getting return back in my arms and somewhat

in my hands and stuff. At that moment everything just shut off again, so I had nothing going on. I tried to explain to them that my neck was rebroken, but they didn't believe me. They just thought it was they had switched the morphine into the next one down--what's that stuff? The other narcotic--I want to say Percodan?

Breslin: Demerol?

Pachovas: Demerol. So they switched over to Demerol and they thought it was some sort of Demerol hallucination or something. I said, "You know, my neck has been broken." They said, "No, no, no, that's just a spasm." Well, I didn't know what a spasm was. I said, "But geez, that was so painful. Is that going to happen again?" They said, "Oh, yes, that'll happen all the time." I thought, "Oh, no, this is not good."

Well, every two hours they would roll me from the back to the front on this circle electric bed because I already had huge ulcers running down my back. The stretcher was obviously smaller than I was and so I had these pressure sores going all the way down like stripes all the way down my body from lying on that stretcher for four days. So they treated them with benedyne and they kept turning me every two hours.

Every two hours I had to play this game with pain where as I would go up and have gravity pull me down and away from my Crutchfield Tongs, that the pain from those dislodged vertebrae would start to really impinge on my spinal cord again and create very bad pain. I still remember now dealing with it. Like, "Okay, if it doesn't get any worse I can stand this." And it would get a little worse. I would say, "Okay, if it doesn't get any worse than this I can stand it," and it'd get worse. All the way up and then at some point I'd just pass out from the pain; it'd just knock me out.

Every two hours for eleven days they did that. My mother got where she just couldn't stand to be in the room. She just left.

They came in on the eleventh day: they had me do x-rays. Then the doctor came in and said, "You know, I don't know how to tell you this but it seems like the bone block has slipped out of place." And at that point--during that experience I learned a lot about blind faith and the main point was never to have it. Never to trust anybody with your body.

Breslin: Did you believe that the pain was the result of change in drugs?

Pachovas: Absolutely--no, no, not the change--I knew it was related to my breaking my neck.

Breslin: You knew that you had reinjured your neck and you couldn't get their attention.

Pachovas: Yes. I couldn't get them to believe it, no. When they took the x-rays it validated it and they had to redo the surgery. It took another five or six hours. But this time they put in two platinum wires and three screws that are still floating around in there to make sure that didn't happen again. But I had lost a lot of function during that period of time and was basically starting over at zero anything. I have no sensation below my neck, no movement, no anything.

Well, we redid the surgery and made it through again. My strongest memory of that, other than just wanting to look forward to something--because it was all like one long day punctuated by this pain--was that I was trying to figure out what the heck to make of all this stuff.

I wasn't quite sure, you know, where do you go from here. I'd never heard of anybody living. There were like three circular electric beds next to mine, so obviously somebody else had had that happen. I had these conversations with the guy in the circ-electric bed next to mine (who ended up being a family friend who was an officer named Carl somebody or other. I can't remember his last name, now) and he'd broken his neck and got nearly total recovery from it.

My mom had the most interesting comment about it all. Because she was trying to make sense of this experience, she said, "Well, why don't you look at this as maybe this is God's way of telling you to slow down." [laughs] I reminded her she said that at a family reunion we had about ten years ago. She said, "Oh, I guess I was wrong about that. Didn't seem to slow you down much."

Breslin: Were you talking with anybody during those first--what is this --a couple or three-week period about any of the indications of your injury?

Pachovas: None, nothing.

Breslin: This was straight intervention--triage? Nothing else going on?

Pachovas: That was it. Nothing. Well, except occasionally a doctor would come by and say, "If you can do this, then maybe you'll walk again." Or a doctor would say, "You'll never be able to

walk again." There were people coming in to tell me this. That's all I want to know--what's going to happen next? It was always from a doctor. The doctors wouldn't be able--he'd either say, "If you can do this, you'll be able to walk again," or, "You're not going to have any return and you'll have to just get used to that. But you still have your brain." But you know, I was a very physical guy, so that wasn't a lot of solace to me.

So exactly a month after I'd gotten there, when I'd stabilized enough to fly again, they flew me to Andrews Air Force Base.

Rehabilitation in Chicago, 1969-1971: Fighting the Medical Regime

Breslin: How much time had gone by?

Pachovas: A month. I think to the day it was a month. At the end of April they flew me to Andrews Air Force Base. Coming down they gave these pilots real instructions not to come down too rapidly because they didn't want me to throw up and aspirate. But they did come down too rapidly and I did throw up. I didn't aspirate, but I did throw up.

When we got to Andrews Air Force Base it was almost a mirror image of what I had first gotten into there at Wiesbaden. Everybody was screaming and the place was so chaotic that they couldn't even clean the vomit off me for a couple days. They just couldn't get to it. I was alive, I was doing a lot better than a lot of guys they were dealing with, and so it was a lot like just being in hell.

Breslin: This was because there were so many Vietnam vets?

Pachovas: Yes, that's right.

Breslin: That they were trying to--

Pachovas: That's right, yes. That's where they were ending up, is right where I was. They were just trying to keep people alive at that point in time. So things like bathing--you know, making sure I had something to eat was probably done, but bathing could wait until I had a greater priority. "We're going to get around to you, but there are other guys that are dying. We've

got to put an IV in and that kind of stuff." So that was happening a lot.

From there they sent me to Michael Reese Hospital in Chicago.

Breslin: How long were you at Andrews Air Force Base?

Pachovas: Not too long. I don't recall. It was about a week, because they had to make some arrangements at Michael Reese. So then they sent me into Michael Reese and they put me in a private room with a nurse sitting by my bed twenty-four hours a day. I was in like very critical condition and I think they just didn't expect that I was going to live and so they had somebody just sit there twenty-four hours a day to stare at me. Kind of weird.

Breslin: Hm.

Pachovas: As I got better, then they sent me over to Rehab, the Rehab [Rehabilitation] Institute of Chicago, because they said that would be the best place to do my rehab. So I stayed another month and I guess I stayed a month at Michael Reese on this twenty-four-hour nurse thing and then they transferred me over to RIC.

They kind of wheeled me into RIC and just left me sitting in this room, staring at the ceiling. I was very depressed. There were these two guys that were in my room who were also quads and one of them was totally covered all the way over his face with a blanket. I don't know why. I don't know whether he was cold or what the deal was, but it wasn't a very cheery kind of thing. Then I spent two years in rehab there.

I had already developed "don't trust doctors" as a general rule. I wasn't going to let anybody do anything to me without my permission. That was never going to happen again in my life. That was not going to happen that I was going to trust someone. So that fundamentally changed the way that I deal with institutions of any kind. I don't trust just because they are an institution that they do what they're supposed to be doing and that it's in my best interest. So I think that that fundamentally changed my political outlook as well as a number of other things.

During that period of time--it was an outrageous time--to be in rehab. If I had to be in rehab, that's the time that I wanted to do it, because there were so many things going on at the time. You know, nobody had ever thought about the notion

of independent living that they were talking about. Jesus, that was a foreign concept. They were getting you ready to go to the home.

You had two choices then. You could either go back and have your parents take care of you or go to a nursing home. They had their whole regime planned around you're going to a nursing home. They would do things like they would put suppositories in when you didn't have to go to the bathroom, you know, and not time it. You had to get up when they had you get up because they had a bunch of patients to see. They tried to get you to fit into the medical regime, because they were certain that's what was going to happen to you. And when I would resist that they would ask me questions like, "Well, what do you think is going to happen when you get out of here?" I said, "I'm going to find an apartment, I'm going to get a job," you know. "Well, who's going to take care of you?" I said, "I'll hire people to take care of me. What's the big deal? You know, I don't need somebody in my life all day." This was such an alien concept. You know, they just thought I wasn't being realistic at all. They even wrote that I didn't have realistic expectations.

They had a lot of rules in rehab then about non-fraternization between patients and the staff which I totally destroyed. Being in a hospital situation and being on a schedule required that you submit to that kind of lifestyle. I wasn't into doing that. I'm going to go to the bathroom when I felt like I had to go to the bathroom, which precipitated another one of those conversations about, "What are you going to do when you get out of there?" I said, "I'm going to go to the bathroom if I feel like I have to go to the bathroom." "Well, how are you going to do that?" "I'm going to hire somebody and tell him I have to go to the bathroom, but I'm not going to do a suppository and get up and shit on myself later because it isn't working. That's a stupid plan."

I had sensation and the orderlies there didn't really realize that you could have sensation if you were spinal-cord injured. There were a lot of things that they didn't know. And I think that spinal cord injury was relatively a new thing --especially at that level, during those days--for people to live. I think the average life expectancy in '69 was maybe four years.

Breslin: For a quad, or para, or both?

Pachovas: I don't remember. I think both. I think both, because I remember saying that that was if. Well, if you lived--if you

lived the first month then your life expectancy was like four years. We were all kind of pissed. That was the predominant thing: "You are a patient."

Well, it turned out that I got--luck of the draw, I got a great doctor--John Spiegler. You know, by that time I'd seen enough doctors and asked enough questions that I knew how to interview a doctor. And the first question I asked was, "Am I ever going to walk again?" He said, "Beats the hell out of me."

Breslin: [laughter] Well, there's an honest answer.

Pachovas: He said, "You know, a client of mine--a patient of mine asked me that one time who had a walker--and I told him he wasn't going to. About two months later he came walking into my office with a walker held over his head, so I have quit being a psychic. If you can walk again, you're going to walk again. And you know how that's going to go." I said, "Well, what about children? Will I ever be able to have children?" He said, "You know, I don't know. Why don't you go out and try it and figure it out and when you know, let me know."

Breslin: Come back with a report.

Pachovas: Yes, he said, "We don't know. We don't know much about this stuff with quadriplegics." I mean, they had dealt with, you know, the paraplegic stuff for a while, but the quadriplegics still weren't living much during those days, so we were rare who survived that. Suicide was the second cause of death among quads at that time, with respiratory problems being first and then the bowel and bladder stuff, uremia being third, I think.

Ah, he had an attitude that I liked. Number one, he wasn't God--didn't know all the answers--so I trusted this guy and then he really did look out for my best interests.

I had some very initial conversations with him about not wanting to be treated like a patient that he totally agreed with. He said, "Well, what do you want to do?" I said, "I want to just get out of here and go back to work as soon as I can." He said, "Well, that's fine, let's try to do that." I said, "But I really don't want to be a patient; I want to be able to come and go. I want to try to be social. I just don't think that being here and staying here and being like this is very healthy." He agreed with that. So he really fought the system for me, you know, and changed a lot of the ways that they had to deal with us. You know, I was the first person to just get passes to come and go as I pleased. Provided that I

didn't miss any therapy appointments, I could go out for the night, come back if I wanted to, go back out.

Breslin: The issue at that point really was that you didn't even need to be in rehab for two years, but you were in rehab because you didn't have a place to live.

Pachovas: No.

Breslin: No?

Pachovas: I was in rehab because I had to lose a great deal of weight.

Breslin: Well.

Pachovas: I weighed 365 pounds then and they knew that--and I mean, medically, that's the only reason I was there.

Breslin: Well, but that's a made-up reason to keep you there.

Pachovas: It wasn't. It wasn't.

Breslin: Everybody believed this was real, rather than--

Pachovas: Oh, no, the staff after I got there wanted me out of there, but Spiegler knew that if I was losing weight there it was going to help me in the long run. He knew that if I went home and ate Greek food and all that stuff, that wasn't going to be happening.

So whatever was going on in Spiegler's mind about what's in my best interest, he was sure that losing weight was number one and that I could do it there because I was doing it. You know, I was eating dexatrin to diminish my appetite and quaalude [laughs] to be able to go to sleep--from the dexatrin at the time--but I was losing a lot of weight. I was on a 600-calorie-a-day diet.

Breslin: Losing brain cells in the process.

Pachovas: Oh, yes, yes. I don't know if I had before, but I'm glad I had some left when it was over with. So it was kind of an emotional trip, you know, between the speed and downers.

Breslin: Why don't we stop at this point?

Pachovas: Okay.

II EXPERIENCES AS UC STUDENT AND ACTIVIST IN THE DISABILITY RIGHTS MOVEMENT

[Interview 2: August 5, 1998] ##

Return to Family Home

Breslin: Michael, we ended the last time talking about your stay in the Rehab Institute of Chicago. Tell us a little bit about what happened as you were preparing to go home and after you went home.

Pachovas: Well, my discharge came rather suddenly and coincided with my doctor being transferred from that hospital to another hospital. As soon as he was gone, I was out, so there was no real post-planning that happened. They were just so anxious to be rid of me that that worked out just fine for them. I ended up just being told, you know, on a Monday that I was gone on Wednesday.

I wasn't quite sure what I was going to do from there, so I went home. My parents kind of put my hospital bed in the living room. My grandfather was also there and living in the living room. He was dying of cancer. All the bedrooms in the house were upstairs, so we converted the dining room into a big bedroom that we shared.

I went home and, you know, mostly kind of went nuts. Didn't know what the heck to do with myself. It was wintertime, and it was just--it wasn't quite spring--but it was wintertime and it was still snowing and I'd think about all this stuff.

Breslin: I bet.

Pachovas: Trying to figure out what I was going to do next. I didn't think I wanted to stay at home, but I didn't know what options

I might have. I thought I was going to maybe get my own place. That was kind of a scary notion.

I had to start getting attendants right away, so I called some of the neighbors up, you know, and let them know I was looking for people who might want work, and ended up hiring my ex-girlfriend's younger brothers for a while and they did some work for me. On occasion I would hire one of my brothers or sisters to do some work for me, but it was a pretty tumultuous time around the old Pachovas homestead.

I guess a few of my siblings had moved out. I had one brother who--I guess he was in the air force when I first moved home--and then moved back. Three of my brothers went in the armed service. None of them finished a whole term in the armed services. They just couldn't stand it. You know, I think the feeling was mutual, so they all got out and then came back.

My brother Gus and I used to get into some real warfare because he seized the opportunity of my being disabled to be kind of the bully on the block which I didn't cotton to very much and so we went at war with each other for a while.

And my dad and mom were still working, you know, trying to make ends meet.

I was living at home, paying rent, and trying to figure out what to do next. So one of the things I did was that I had some money saved up and I bought a car. I bought a Lincoln Continental which turned out to be just a wonderful notion. It had big suicide doors on it, a '69 Lincoln Continental. It was really easy to drive and I found it wonderful to just sit in it. I could go anywhere I wanted and it was more comfortable than my wheelchair.

Breslin: Were you actually able to drive it?

Pachovas: Oh, yes. Yes, I drove it. It had air-conditioning and it had the full boat--a nice stereo--so I would drive and go places.

At that time, my friend Michael George, who inherited millions of dollars when he turned twenty-one, decided he was going to start a medical supply dealership in the outskirts of Chicago in South Chicago, so asked me if I wanted to work with him and help him build the business up. I said sure, so my first job out of there was helping him sell medical supplies.

First Organized Consciousness of Disability Rights: The National Paraplegic Foundation

Pachovas: In the course of my doing that I ran into a group of people from the National Paraplegic Foundation [NPA]. Didn't know anything about the National Paraplegic Foundation, just heard that there were some people that met occasionally. I thought that might be a good place to go sell some medical supplies, so I went to one of their meetings. I was really pleased. Here was a group of very rowdy paraplegics in the Midwest, who were talking about ramping things and getting things done. 1971, that was kind of heresy. You know, I thought, "Great! Great! Geez, at least I get to deal with some disabled people that aren't complaining about how bad their doctors treat them and how lousy the hospitals are and whining all the time."

Breslin: Not in a rehab setting.

Pachovas: Yes. These were like actual living people that were living in the community and doing their own thing. You know, when I think back on this independent living thing, I realize that it really has been going on for about ever, but we hadn't really institutionalized it as a thing until the late sixties and the early seventies when we started forming institutions to serve us and getting some more organized political muscle. Back then about the only real organized political muscle disability-wise, and if we exclude the sensory disabled people who have been around for aeons, was the Disabled American Veterans, the Paralyzed Veterans of America, you know, and then the National Paraplegic Foundation.

So the first bit of rowdiness I ever got involved with--organized rowdiness--was we had heard that the county was going to build a new library and they weren't going to put a ramp on it. They weren't sure what to do and I said, "It's easy, [laughs] we'll just call them up and we'll tell them that we're going to go and we're going to show up on Wednesday to thank them for making their new place accessible." They said, "Well, they're not going to make it accessible." And I said, "Well, let them explain it to the press." [laughs] So we horned in on the press conference and thanked them for making it accessible, and they felt somewhat on the spot and made it accessible. So and we went on from there.

During that time I fell in love with this beautiful woman who was a disabled woman, a paraplegic. And on that level things kind of were okay for me, you know? I had good friends that were forming on the outside and there was somebody I

loved. [Macaw screams]--hang on for a minute. Let me shut the door. [tape interruption] You know, I started developing a social life and a more conscious organized approach toward disability civil rights.

They were a group of very exceptional people. I was real pleased with them. They had the same kind of spirit that it seemed to me that I did and that was somewhat of a rare commodity during the time that I was at Rehab.

Family's Reactions to Disability

Breslin: But you were still living at home in the front room, or the living room, is that right?

Pachovas: I was, yes.

Breslin: What was the reaction of your family to your disability?

Pachovas: It was very mixed. It was hard; it was mostly not very good. My father just kept saying, "Well, why don't you go back to Rehab, maybe they can make you better." He had no consciousness about it. It was kind of a dichotomy: on the one hand, he enjoyed getting the sympathy of having a disabled son and saying that he had one and then on the other hand, I had gone immediately from being the chief asset in the family to the chief liability. There was no bones about it. It was just the way it was. So he wasn't too pleased with my having to be home and not doing what he was doing. He had wanted me to eventually run the family business which I had no interest in doing whatsoever.

We'd had a falling out when I left for the Peace Corps. As a matter of fact, when I left, the day he was seeing me to the airport it was still hard for him to really understand that I was really leaving and I was on my way to Africa right at that moment. You know, he said, "Well, don't come back." I said, "Well, Dad, you know, when I'm done I'll be twenty-one and to be honest I hadn't planned to come back." So he still kind of had that attitude.

Breslin: How about your mom?

Pachovas: My mom--my mom was very supportive. She always thought I could do whatever I set out to do in life and always made me feel that I could.

Breslin: So your mom was supportive of whatever direction you wanted to take?

Pachovas: Yes, and my brothers and sisters were a mixed group. Some were very helpful. Some resented my asking for help and so I tended to lean more heavily on those people that didn't seem to mind, which I'm sure was more of a burden to them. But it was very depressing.

I was incredibly depressed and I began to eat a lot. When I was in Rehab I lost 160 pounds over about two years. Then when I got back, I gained it all back within a couple of years. I just ate candy bars; I was stuffing my face. I didn't know what to do. I mean, I'd gone from where my meals were planned --I knew what they were, it was fairly steady, plus they were like pumping me full of dexatrin and quaaludes--so that I could maintain my metabolism and then sleep from the speed they were giving me for the diet. Then, here I was at home and trying to figure life out and I wasn't prepared to do it. You know, I wasn't prepared to do it.

I'd adjusted fairly well to living in downtown Chicago, and I enjoyed it a lot. I could roll around fairly freely and go to the theater and go to social things and go to the Art Institute and have a pretty good time. And then all of a sudden I'm out in rural Crown Point, Indiana, and it's snowing out and I can't go out the front door. There were literally snow drifts up over the door some days.

The only power chair that I had was my wheelchair that had a motorized unit that I could attach to the back called a motorette. We used to call it a murderette because they were really dangerous contraptions.

Breslin: They sure were!

Pachovas: And my dad unwittingly decided to put shag rugs in the house and really didn't want me to bring the motorette in the house. He wanted it to be kept out in the garage and thought it would be good for me if I learned to push. He was the kind of dad--old world people--that would say, "Get up and change the channel for me." I would have to go push my chair all the way across a really long living room and change the channel for him. It was murder on my shoulders and it just blew out my shoulder sockets from locking my arms and leaning forward on my wheels as hard as I could to move a few inches, which is what they wanted you to do when we were that age back then. It was manly to push your chair no matter how stupid it was.

Breslin: Well, those of us who weren't men--engaged in manly activities would say--[laughs]

Pachovas: Oh, I'm sure! When I say that, I'm not being sexist in any way, it's just the whole cult of able-bodyism hit us full force.

Breslin: Rehab didn't equip you at all to think about jobs or training or similar--

Pachovas: No, not at all, no.

Breslin: Did you have any discussion with anybody there about any of that?

Pachovas: Nothing, no. No, they just assumed that I was going to go home and either live with my parents or go to a nursing home. That was their whole--and I think they hadn't really planned on my hasty departure. At least, the departments that did that weren't in touch with the departments that decided who stayed and who went.

Breslin: I'd say two days is not enough time to plan.

Pachovas: It wasn't much--it wasn't much time.

Move to California to Attend UC Berkeley, 1972

Breslin: So how is it that you came to Berkeley?

Pachovas: Well, so here I was living in Indiana. And life wasn't fun. You know, it wasn't fun. I just felt, you know, that I was a real burden and wasn't sure that this living outside of an institution stuff. There was so much going on at the time. I mean, my grandfather was dying, and there were good things and bad things. I really enjoyed spending the last year of his life with him because I learned a great deal from him. I felt that we had a good understanding of each other and there were a lot of funny things that happened over that time, so it wasn't a totally dismal experience by a long shot. My family was very animated, so it wasn't for lack of something to do, or something going on. It wasn't a boring kind of thing, it was just for me somewhat depressing because I felt so isolated by my disability.

As a matter of fact, one of the things that happened to me when I was at home was that I would be able to get away from the din of all this--the kids running around and yelling and hollering--by just being able to look outside the window, you know, and just concentrate on the snowflakes coming down. I could just kind of isolate myself. Now they call that stuff meditation. I didn't know that at the time. There wasn't such a notion. But I could really, really get into my own bubble there and tune it all out and it brought some sense of inner peace. Actually it lasted a bunch of years for me. A lot of times since, when I got into political situations in later years, I was able to tap into that and still stay calm when things around me were fairly chaotic.

So I did get some good things out of there but, you know, I really began to doubt whether or not it was worth hanging around the old place. I'd thought about, "Geez, you know, is this as good as it gets?" And if so, I wasn't too happy about the notion.

Oh, there was a rehab counselor who was--and it wasn't really a rehab counselor, it was my federal case worker from the Department of Labor--who told me that if I wanted to go to school they would pay for it. I thought, "Well, that's cool." That got me into thinking about all right, well, maybe there's something next to do. So I did--I had planned--I wanted to go back to school and to do something there, so I started looking around and figuring where am I going to go to school.

Well, I'll tell you, the clarity--I don't know if I talked about this earlier--but the clarity that struck me this one day when I was in downtown Chicago about not being there anymore was profound. I'd been going down Lakeshore Drive with my power wheelchair and it was an incredibly windy, blustery, snowy day and about the third snow drift that I got stuck in that a passing motorist had to pull me out of made me decide, "Fuck this, I'm moving to California."

Breslin: Enough.

Pachovas: So I decided I didn't need wintertime anymore: I was going to go somewhere where the sun shined a lot. Some of my friends went to Berkeley who were in the Peace Corps, and it had a good reputation as being kind of a progressive sort of place. So I thought, "You know, I'm going to apply to the University of California." I don't know, that was the main motivating factor, I just applied to the University of California to see if I could get in. I got a letter back saying not only would

they accept me, but they had a place for me to live on campus if I wanted to go there. I thought, "Well, cool!"

Breslin: You didn't apply because you knew there was a program?

Pachovas: No. No, I was just trying to find somewhere to go to school as far west as I could go without drowning. Berkeley seemed to be the place. I didn't even know where Berkeley was. I mean, I knew it was in California, but didn't know it was right on the Bay Area physically, so I was pleased to find out where it was. It really was on the ocean. I couldn't go much further west than this.

When I found out that I could go, I had a long talk with my girlfriend about it. She was really bummed out because she just--she was this woman who was like a runner-up in the Miss Wheelchair America contest--and was the belle of the small town that was near mine and everybody loved her. She was just a wonderful woman. She'd gotten hurt in an auto accident when she was a teenager. A car rolled over during lunch time and smashed her spine. I guess she had just assumed I was going to stay there forever. When I told her I was really going it was very hard for her.

Now, my notion was I was going to go out there--and she had a daughter, Deanna, who I just loved to death, from a previous marriage--and I figured, well, we'd go out here. I'd go out first and set up life and then have them come out. Well, that didn't happen. That didn't happen. I didn't realize how attached people are to their roots. I was surprised when I went home for the first Christmas after I'd gotten out here that she wasn't willing to do that. Then I had to make that choice. That was a hard choice.

Breslin: Yes, I'll bet.

Pachovas: But at any rate, so I decided to pack up the old Lincoln. I bought a trailer. It's a little old wooden trailer, a straight-bed trailer with wooden sides. I packed all my worldly possessions in it that I could haul off and went west.

I was going to take my attendant who was one of the neighbors with me, but school was starting. He was a sophomore, but he was a huge, big guy, and could get me around really easily. So I had to go to the school board and get permission to have him miss the first week of classes. I figured I'd drive out here and then put him on an airplane and send him back when I got here.

My brother Andrew also decided that he wanted to come out here, just for the ride. I thought, "Okay." I wasn't too sure about that, but I figured, okay, I could use a second driver maybe, so I said okay. So we came on this epic journey across country.

Breslin: They're always epic. [laughs]

Pachovas: It was one of the epic journeys. At one point I'd left him standing on the road in Nebraska because I was so fed up with him.

Breslin: With both of them?

Pachovas: No, just Andrew.

Breslin: Just your brother?

Pachovas: Yes. It was quite a crew. The first hour I said, "Now, everybody stay alert because if anything bad happens it'll happen now." [laughs] Just outside of Chicago, these people are honking and waving and I'm waving back at them like you know, oh, hi, really friendly people. Well, my trailer was on fire. I had no idea. I looked in the rear-view mirror and there's smoke coming off the back tires. I thought, "Oh, no, this is not good," so I said, "Hey, Andrew, what's going on back there?" I looked in the back and both Andrew and Mark were sound asleep. So I thought, "Well, it's going to be like that kind of a trip."

Breslin: Not a good start.

Pachovas: No. [laughter] It got more interesting as we went along, but we made it out here.

I remember, still, rolling into California and, God, it was so hot. I had to stop in Davis. In Davis, California, it was a hundred and something degrees. It was around the eighth or ninth of September and it was hot. I thought, "Geez, this is not a good place to be and I sure don't want to live here." It was flat, which I also didn't like.

But I had no vision of what this place was going to be like, so I just kept on driving. Came down to the Bay Area and came over the Carquinez Straits and went, "Whoa, this is really nice!" Then I saw what I thought was the University of California because I could see the Campanile from down on the highway and I thought, "Oh, my God, it's on a mountain side. How am I going to do that?"

So I trucked up University Avenue--now, I'd had no problem driving the whole 3,000 something miles--but I almost got into three accidents just going up University Avenue because people around there drove so crazy. I pulled into the Cowell Hospital on campus, got into the circle. I've forgotten whether I'd called them to tell them I was coming; I must have, because when I got there Edna Brean and David Nadell were there. David Nadell was standing there--now, mind you, this is like almost ninety degrees here in Berkeley, which is a pretty hot day for us--and here's David with a warm blanket and a hot cup of tea, waiting for me. I'm in my tank top and jeans and couldn't figure out what this man was doing here all dressed in white.

Edna said, "Well, ah, ooh, we're kind of embarrassed to tell you, but they won't let you move in here." [laugh] I said, "What? I can't just turn around and go home, you know!" "Well, you're not a rehab client." I said, "So what, I'm paying for my own stay. I'm paying for the room. They're not paying a nickel of my stay here. What's the problem?" "Well, it's just kind of bureaucracy. We're going to try to get it worked out, but you're not an official rehab client. Unless you are, you can't stay here."

So I said, "Okay, well, do you know any good places to stay?" She said, "Well, we called Herb Willsmore up." Herb Willsmore was living with Judy Taylor at the time at a place up on Haste Street and they agreed to let me stay with them for a few weeks while I worked out the rehab problems. So I drove up to Herb and Judy's place and parked the car in the garage.

They had arranged to have Walter Gorman meet me there, who was my first attendant in Berkeley; a wonderful guy. I don't know if you know Walter, but he's this really funny Irish guy.

Breslin: Was he working in the residence program at that time?

Pachovas: I think he was, yes. It was quite a cast of characters that was working at the program at the time.

Impressions of the Disabled Students' Program

Pachovas: So I stayed up with Herb and Judy and tried to figure out what was going on there and started having a good time. One of the things that was going on at the moment was they had rented another apartment right around the corner in that same complex of apartments and they decided to start trying to pull together

CIL. They decided that they needed to start getting together something similar to the Disabled Students' Program [DSP] that they had on campus--it was called the Physically Disabled Students' Program [PDSP].

The PDSP was back behind Top Dog up on the second floor up the suicidal ramp. I met the people who were working up there shortly after and was pretty impressed by their chutzpah. I was surprised to find out that they actually had something organized that was going on. They worked out the red tape so I eventually moved into Cowell Hospital and stayed in the wing there for about--I guess about, I don't know if it was--maybe the first year that I was here, or no, I think it was the first semester that I was here, fall quarter. I think I moved out in the spring to a place over on Ellsworth that I shared with Phil Chavez.

Breslin: Who was working at PDSP when you first met the staff there?

Pachovas: Well, let's see, John Hessler, Don Lorence, Cathy Jay, Chuck Grimes, Andy Lennox, Zona Roberts. I'm trying to think who else might have been around there. Mike Fuss wasn't there then; he had left, I think. Dennis Fantin, I think, was working there then, or at least I got to know Dennis around that place. I can't remember whether he was working there or whether he was a student at the time. That's my immediate recall of who was actually working up there.

Breslin: Was Ed Roberts still--

Pachovas: No, he wasn't even living in the county at that time. He was down at--he was teaching school over at Cañada College. He wasn't living in Berkeley.

Breslin: What was your impression of what was going on at DSP at that time?

Pachovas: I thought it was interesting. I thought it was a smart thing to do. You know, that we'd get our wheelchairs fixed. I mean, I had other things that were going on at the moment, for example, trying to figure out how I was going to get to classes with a motorette and how I was going to get a wheelchair and what was going to get me around and all that stuff. I mean my class schedule was aligned so that I could take classes that were furthest up the hill and at the end of the day I'd have a class that was at the bottom of the hill so that I could just keep on going down.

Breslin: [laughs] The gravity effect.

Pachovas: Yes, that was how I planned my class schedule. On the way back I asked people to push me as far as they were headed in a given direction. So for a whole semester that's how I got back up to Cowell, "Excuse me, are you headed in that direction? Would you mind giving me a shove as far as you're going?" Then when they would peel off, I'd wait there at that intersection and wait for somebody else who might be going in my direction.

Breslin: You weren't using your motorette at that time?

Pachovas: Oh, I was, but it wouldn't get me up those hills. It just chewed up my tires, especially if it ever rained. Oh, god, then they were awful.

Breslin: Hopeless, it was hopeless.

Pachovas: So I was wrestling around with that stuff. They had the whole crew at DSP.

I was somewhat dismayed by the lack of accessible classrooms at the time. It wasn't hard enough having to figure out a class schedule that worked going east to west, but then not being able to take classes that I wanted because they were not in accessible buildings was annoying.

I remember then that I went to John Hessler. I said, "John, you know these classrooms aren't accessible, and we need to make them accessible." John said to me, "Who says?" That kind of stunned me. I did a double take. I said, "What do you mean, 'Who says?' They're not accessible. We need to make them accessible." He again said, "Who says?" I said, "Well, I say!" I said, "What's the problem?" He said, "Well, if you want something done here, you've got to go through me to get it."

I can't tell you how much against the grain, how against my basic ethic, and against my whole essence that that kind of a comment makes. That I have to ask somebody's permission to go do something that makes sense! Well, I pretty much decided at that point that I'm dealing with an egomaniac and I don't think I will; I think I'll play a different game.

So I talked to some of the students at the time, and we started the Disabled Students' Union. We decided that the disabled students' program was an office of the University of California and that we wanted our own voice, thank you. So we did. We started the Disabled Students' Union [laughs] largely because of John. John later said, "Well, you got to be proud

of me, I started the Disabled Students' Union," [laughs] in his own sort of annoying kind of way.

Breslin: So that encounter sort of set the tone between the two of you?

Pachovas: Yes, it sure did. Yes, it sure did for a long time. He was pretty full of himself during those days. I mean, we all were. I think younger people today don't really realize what it took to be there then, and that it took a kind of person that was not cattle and one of the herd.

Breslin: Why do you say that?

Pachovas: Well, life today is not very easy if you use a wheelchair to get around, especially if you're quadriplegic and you have to work out attendants. To have everybody be able to go to one place at one time and start something and get it going, it's a pretty enormous undertaking. That takes people that aren't willing to take no for answer. And I think most of us up there were like that. I mean, some of us were quieter about it, but we were all pretty determined that we were going to make our fate.

For whatever reason we all decided that home was not the place we wanted to be right then in our lives. So I think that it took a lot to push me on that. You know, I was living in the middle of Africa at twenty years old, so I had a pretty good sense of self and that I could do okay on my own; but for a lot of people there, they had never done anything like that before. To make that kind of move is incredibly heroic.

I was constantly amazed at the amount of physical pain and suffering people had to endure, you know, to deal with that stuff, and the amount that they would put up with. How smart everybody was and how into this whole notion that we're going to make something happen here. That was starting to build and starting to build. I mean, it really started trickling. And then the trickling became streams and then the streams became a torrent and then a river. It wasn't something that just happened over night. I would say the formative stuff took maybe about a ten-year span.

Breslin: From what to what?

Pachovas: I'd say from around '68 to '78 was the crux of it, you know, in getting into those times. Then we started forming lots of institutions. Then we all went to hell.

But there was a good sense of doing things together. Even though John and I had had our early disagreements and all that kind of stuff, when things had to happen, you went, you know? You just went.

Then there were all these power wars that were going on within the disability community that I pretty much tried to stay out of--because Larry Langdon and then Larry Biscamp were then the directors of the Center for Independent Living, which had just gotten its first funding around '73 I guess--and Ed came back to town about that time and he wanted to take over.

There were very hard feelings within the structure of people who worked at CIL about whether to continue on with Larry and Larry, who in everyone's opinion weren't great administrators, but who were nice guys. Both of them had more balls than sense. I mean, Larry Langdon--I went out with Larry one night when he was drunk in a bar--and his tactic was to be really loud and obnoxious and if he got into a fight with someone he would grab him by the throat, pull himself up out of his wheelchair and punch him as hard as he could and hope that he knocked him out because he knew he was going to get his ass kicked if he didn't. That's the kind of guy Larry was. And [laughs] Biscamp wasn't much different. Biscamp thought small arms were the way to go. So. [laughter] So they had the right stuff.

Breslin: Oh, admirable refinement around the edges.

Pachovas: So Ed came. Ed had the political savvy. He figured out what had to be done and got together with John and decided they would pull a coup and off the leadership. At that time, it left a real bad feeling, especially--and I never knew exactly what the feelings were all about--within the blind contingent that was then working at CIL. A lot of the folks that had formed the blind counselling program left at that time, or resigned from the board of directors.

Breslin: And who were those people?

Pachovas: You know, I think it was Jan McEwen, Richard (Dick) Santos. Geez, I can't remember exactly who all was there then. They were on the board back then. I think they both came back and worked with them once they got the vote out of the way.

Both Larry [Biscamp] and Ed really wanted to get my support to have them go be the director of the CIL and I just wanted to stay out of it. I was busy enough. I was trying to work with

the students on getting the campus accessible. We were trying to move the program out of the dormitory--I mean, out of the Cowell Residence program and into a dormitory--against John Hessler and the Disabled Students' Program's wishes, so we went to battle with them for two years to get that thing moved into an integrated facility.

Breslin: Why was John opposed to moving the program?

Pachovas: I don't know. It wasn't anything rational. I think it was more because I wanted it to be in an integrated facility and [he] felt like that was his call to make. I think it was personal.

Breslin: Did you ever talk to him about it?

Pachovas: No. [laughs] Not really. You have to realize that John and I really would hammer and tong, so we didn't share much.

Breslin: I wondered if at a later time you might have had a chance to bury the hatchet?

Pachovas: No, he died right after that. Well, right after that he had a nervous breakdown and he went out to Antioch to live. Then Ed had moved from CIL at that time over to the Department of Rehab when Jerry [Brown] came in as governor and then pulled John up to do some education stuff up in Sacramento with him, so I never really saw John much after that.

For as vitriolic a relationship we had, we had this grudging admiration for each other. If there was anybody that attacked either one of us we would both jump in there. I'm sure that that feeling didn't leave, but between the two of us there wasn't a lot of good stuff to be said.

Allegiances in this town, especially around that time, became very bifurcated. We saw lots of camps that were forming. Some around the Langdon and Biscamp stuff and some around the Disabled Students' Union and the Disabled Students' Program.

I think overall it was kind of an interesting time because it was almost like the counter revolution came to town. And how would we deal with it when we formed our own institutions and people were complaining about it. There isn't an easy answer. There still isn't an easy answer today.

One of the things that we were struggling with at the time was that when he took over as director of CIL Ed wanted everything to come under CIL's umbrella: every program, every notion, everything that happened. There were a lot of people in the community who didn't want to do that. They just wanted the independence to go off and do their own thing and found that CIL had become an obstacle to their doing that if they didn't have the good graces of CIL's permission. So some of that early animosity sprang from ideological concerns about whether everything should be under one roof or everybody should be independent and yet have some sort of loose network that worked together.

Breslin: And what was your point of view about all that?

Pachovas: My point of view about it is that I think that we create our own institutions which undo us. I think that we need to have a movement, and I think that we have to have organization and that we will create institutions to be able to perform that because that's what society as a whole does; but once you get into an institution-like situation, you're locked into a certain dance that you can't get out of. So you may have the same freedom and the same tools that you have to operate as when you're a movement. When you were a movement, you can just take your whole operation down to the mayor's house or down to the governor's house and camp there and not care if you're sitting in jail. When you're an organization, you can't do that very well and still get funded.

Breslin: When you say movement, you mean an ad hoc group?

Pachovas: I'm talking about a group of more than two people who want something done and can't get it done, yes. I mean, it doesn't have to be--for god's sake--the last thing I'd want to do is to start another organization. I mean, there are enough organizations that are out there. The healthier thing I see is that there are some coalitions building.

But I think that we do a lot of things for the younger people coming along that aren't so good. That's mostly to keep them out of the decision-making. A lot of what was happening in those days is that those of us who had political clout would be seen as speakers. We would go to different things and they would naturally say, oh, you represent this faction, you represent that faction, whether it would be blind or disabled students, or whatever, and therefore you should speak about those issues, or represent them at whatever rally or function we were having. Well, you know, we would drag everybody out of

bed to show up and they would go to jail just the same way we did. Nobody ever shoved a mike in their face and they never got much of the press. I think that we alienated a lot of folks because of that stuff. A lot of us were alienated in turn because you weren't or you were in one particular clique or another.

Recalling the Cowell Residence Program and Rehab Counselors

Breslin: Well, look back for me for a minute at the residence program, especially when it was at Cowell. The program was comprised primarily of men, is that right?

Pachovas: Yes. Mary Anne Hiserman was living there at the time. She had a double room at the end that we always envied.

Breslin: She was the only woman in the program?

Pachovas: Yes.

Breslin: Why do you think that was?

Pachovas: And then later Cece [Weeks] came in and some other women.

Breslin: Why do you think that it was primarily men?

Pachovas: Let me just talk about quadriplegics. Most of us who are quadriplegic are men. It doesn't happen to that many women, you know, as a percentage. Something like 80 or 90 percent are men, so I think there's some natural inclination that that should happen just demographically. And I think that especially during those early years that women were much more sheltered by their families and were much more taken care of in a sort of way that men weren't. Men were expected to go out and, you know, carve a new frontier; and women weren't in those days.

As a matter of fact, a lot of our organizations were as good as they were because we had this huge pool of available disabled women that were really smart and had no jobs. I think that pushed our agenda along real fast. When we got here, I think that we were about 500 years behind civilization and now I think we're only about 100 years, so we're gaining fast.

Breslin: What was the role of the [California State] Department of Rehab as you remember it, in DSP or the residence program?

Pachovas: Well, it sure depended on who you had for a rehab counselor. They didn't know. They still don't know. Go ask them. I had a really bad rehab counselor in the beginning who insisted that my career should consist of getting a bachelor's degree in psychology. Now, at that point I decided I was going to go be a psychologist. "You've got to be a Ph.D. to be a psychologist." I said, "Oh, no, that's not what I want to do." They said, "Well, we won't let you in this program unless you do." "But that's not what I'm going to do. You're not paying for it. I am. What is your problem?" "Well, I won't write that down as your career." I said, "I don't really give a damn what you do, lady."

Later I got Karen Topp as one of the rehab counselors.

Breslin: You had a state rehab counselor separate from your relationship with the Department of Labor?

Pachovas: Yes, and the deal was--

Breslin: And they advised you?

Pachovas: The rehab counselor told them what they should spend money for me on, and it came out, [laughs] none of it came out of state monies. It just got passed along. Unfortunately for me, I had a lot of counselors who didn't tell me what my real rights were. For example, I didn't know for nearly twenty years that I was able to work and not lose my benefits. That really changed the kind of major that I went into. Back then, you could pretty much get a van if you were severely disabled and had a good work program.

Now ironically, when Ed [Roberts] came in that stuff stopped.

Breslin: It did?

Pachovas: Yes, it stopped with his administration. Vans were no longer on the gimme list, so then it went back to typewriters and computers and things like that that were starting up. It was too bad. I was right on that border line, too, of being gonna get one and then ended up my first year of graduate school finding out that they were going to quit doing it.

Breslin: What kind of memories do you have of Karen Topp? You said she was your counselor?

Pachovas: [laughs] My best memory of Karen Topp is one that she narrated to me later. She said, "You know, the first time I met you, you were riding in John Hessler's van and the two of you were shouting at each other at the top of your lungs for about an hour. I was really intimidated because I didn't want to get involved in the middle of this argument." My recall was that it had to do with the Disabled Students' Program moving the residency program at the time. But she was very young and eager and naive and liberal and we changed most of that, except for the eager and liberal part.

Breslin: [laughs] How do you mean you changed it?

Pachovas: I think that she got quickly educated about what we were all about. I think that the paternalism that comes by being a counselor to somebody who has a severe disability diminished with time and she started realizing that we were as rowdy and tough as she was if not more so. As I said, I know we were a sassy group back then.

Unfortunately I think that institutionally what happened was as we became more and more rowdy the University of California--and I know this for a fact--started to recruit more people that were less aggressive and less intense and more studious and academic. I think that changed the gene pool here in Berkeley, so to speak. [laughs]

Breslin: You think that the university deliberately recruited for a different group of people?

Pachovas: Absolutely. Yes. Without a doubt. As a matter of fact, we had wanted--one of the things that was going on back then was I'd worked with some students to start the California Coalition of Disabled Students--and what we wanted to do was get enabler programs in every college campus. We had four systems: we had the state universities, the UC system, the private colleges, and the community colleges and so we all had representation from each of those groups. Then once we had three votes--and then ultimately nothing happened as far as a body.

It was a good group of people and many of whom I still see, you know, being out there, being rowdy, being leaders, doing a lot of very good things--Betty Bacon, Ray Zanella was back there then, a lot of folks--Dennis Fantin--it was an

interesting group of folks. And they carved new turf. I think Hollyn Fuller was back there then. A lot of these people I still know today, because of those old kind of times.

Oh, I just lost my thread here. I was trying to respond to something you said and I just forgot what it was.

Breslin: Well, I was interested actually in knowing what your memories and recollections are about Karen Topp and whether you thought that she played some important or other not important role at the time?

Pachovas: You know, I think she did the best she could and probably the best anyone did at the time. She was really good with John Velton. John wasn't as malleable as Karen, but he just had the best heart in the world.

Breslin: And John was the--

Pachovas: He was her supervisor. I'm not sure what his title was. They had great pride in the Cowell program because that was their baby and so we had to convince them that it was a good thing that we were moving into an integrated situation rather than continuing to be segregated and telling people come up and visit us in our hospital rooms. You know, we just felt that there was such a social stigma about that. Not that we didn't have a great rowdy time up there. We had some great times up there! You know, definitely x-rated times up there! But it was still weird bringing somebody up to a wing of a hospital, you know, to come up and hang out. It wasn't like being a student. It was a little different than that. And we were still this other or this special kind of thing.

Breslin: So you stayed in the Cowell program a semester you think?

Pachovas: Yes, I believe so.

Breslin: So how'd you make the transition out of there?

Pachovas: I started looking for an apartment. And at that time--let's see who was--David Nadell or Paul McBride was working for me back then. There were a lot of people that were still in the community going in and out. Bronson West was doing attendant work back then. A lot of very interesting people.

I remember one time when we had--we had this guy--what was his name? Rutledge. John Rutledge. Do you remember him at all? [laughs] Boy, John drank. He was a drinker. That guy

was a party kind of guy. Well, his dad was like one of the first POWs [prisoners of war] to be returned--

Breslin: Oh, is that right?

Pachovas: So he was a major in--I can't remember what branch--but I do remember one of the best things that happened was there was this big PR thing about Dad Coming to See Crippled Son at Cowell Hospital and there was this big, huge press thing. Well, you know, we didn't pay much attention to it. Back then, you know, everybody was like organizing against the war, so it wasn't a very popular thing to be a big militarist or anything. Well, [laughs] one day I was sitting kind of around the reception area. There was an elevator and then you went around the corner down the hallway. The door opened up and more brass dripped out of that elevator than I had ever seen in my whole life--just nothing but stars coming down the hallway--to make this whole PR thing. And Walter Gorman was coming down the hall chanting, [sings] "Ho, ho, ho, Ho Chi Minh." And it's just this wonderful like, "Oooops," banging into each other.

Breslin: All right. Hold that thought.

##

Breslin: Finish your story about the visiting brass.

Pachovas: Well, that was pretty much the end. They came and visited. John got too drunk to stay in school and John dropped out. When they realized that there was no way, no how, no matter how much pressure, no matter how much pressure of military power, could you retain an F average and stay in school, even if you were one of the anointed and lived at Cowell. So he kind of went by the wayside.

A lot of friendships were built there that still are maintained, you know, oh, god, twenty-five or twenty-six years later. So that was a good thing. And I think, you know, there is still the old guard in Berkeley. I'm not sure when the first wave ended and the second wave began. I'm feeling more like I was part of the second wave than the first wave, just because of the split that we had with the Disabled Students' Program and then with Ed coming into town right about the same time and divvying up the power structure over at CIL.

Relationship with Ed Roberts, Assessment of His Leadership of
DR and CIL

Breslin: Did you know Ed well?

Pachovas: Well, yes, I did. I knew him real well. I used to hang out at his place a lot. We used to talk and, you know, were very good friends at one time, and then fell out.

Breslin: What was the falling out over?

Pachovas: The falling out was over his going up to Sacramento at the time he did--to take over the Rehab directorship [California State Department of Rehabilitation] and not leave anybody to pick up the mess he'd left behind. My concerns that CIL was going to fall on its ass when somebody started really looking at the books. I knew what was going on because my girlfriend kept the books, both sets of them, over at CIL. We were in a place where Ed was just sure that his charisma would continue to bring in enough new monies that it didn't matter that we were building up a work force over there that we couldn't sustain economically. We were bringing in people to work on new projects and to do more work using monies that were meant for months eight, nine, ten, eleven, twelve on existing grants, assuming that the grant would be refunded and it wouldn't be a problem. But at some point, you know, an idiot would see that it was going to build up and come crashing down.

Breslin: Did you have a formal role at CIL at this point?

Pachovas: Only once in life. It was a payback--it was a political favor to Peter Trier--only to be on a reform board of directors over at CIL to try to bring it back in the community and my being there would have made a difference.

Breslin: When was this?

Pachovas: Oh, Lord. When was this? Late seventies, before 1980 and after '77. Can't remember exactly.

Breslin: But your concerns about Ed's tenure had to do with his management of CIL before he left and the lack of leadership after he left?

Pachovas: Yes, I mean, you know, I wasn't as concerned about the lack of leadership because I think that with the people there, there was enough of that to go around. I wasn't sure. I knew that nobody had the same savvy that he did. Judy [Heumann] had

savvy and she came into town, you know, shortly after that. I remember the first night she met Ed, I happened to be over at his house and that was kind of fun. But it was a different kind of savvy.

Breslin: What did Ed have that was unique?

Pachovas: He had the ability to understand where we stood in terms of current events and how to capitalize on that.

Breslin: What's an example of that?

Pachovas: All the seed money grants we first got. And his escalation, you know, to the head of the Department of Rehabilitation in the state. I mean, he did have a real penchant for self-promotion. He was good at it. [pause]

I remember I was with him a number of times and we talked about some of the things--how far we could stretch things--without really getting smacked by somebody.

Breslin: What does that mean? What do you mean by that?

Pachovas: I'm trying to think of some concrete examples. [pause] One was moving from the old building on University Avenue to the new structure and taking out a huge note. I remember one meeting we had where we knew that we couldn't pay the rent. [laughs] There was no way. His attitude was, "They're not going to foreclose on us, we're cripples. It's not going to happen."

Now some of us on the board were freaked about that whole notion--you know, who were around the scene and went to sit on the board--because a lot of what went on at CIL didn't have to do with the board of directors. It was mostly about what was going on with the director, whoever the director was. There were intense loyalties and disloyalties built around things like that.

Again, there was a lot of clique stuff going on. You either really fell in line there, or you got smacked, you know. And there were a list of dead bodies politically that came out of that fracas. People were still working on their own, independently, quietly, who don't want, you know, don't want to have to ask anybody for permission and don't want to have to get anybody's blessing--all that kind of stuff.

Breslin: When you say fracas do you mean what happened when Ed left, or are you referring to something at a later time?

Pachovas: Well, during his tenure. I mean, there were a lot of people that got somewhat disenfranchised by that whole approach and pushed out of the fold. I don't know--you know, the Berkeley Outreach Recreation Program moved out of that, the Disabled Prisoners' Program moved out of that, there were a lot of things that were going on in the community independently and started to happen--DREDF--a number of other organizations that wanted their own autonomy.

Breslin: Ed left when?

Pachovas: When did Ed leave? Was it '78? It was '75. Ed went up there. At that time Jerry [Brown] was trying to get him to be an assistant VR director of the Department of Rehabilitation.

Oh, that's a good example. Ed felt that we had the political savvy to back Jerry down, and let a cripple run their own business up in Rehab. And so he did. He took over. You know Ed--and here's another example--at one time Ed had enough money--they gave him enough money--to start eight independent living programs and run them. So Ed started twenty-three but with the same amount of money and may have made some close their doors because they didn't have any continuation money later. But it went on the resume as twenty-three independent living centers started, you know, and moving on. So he's kind of our P.T. Barnum.

I'll take nothing away from him, that guy really pushed this whole movement along, you know. It's kind of like having a brother you love to hate. He was more like family than--or at least as much like family--as much as my other brothers at the time. We did a lot of things together that were fun. You know, I have some fond memories of all that time. I guess I can even kind of remember our falling out. That was when we were both on Sacramento Street, and I said, "Ed, you know, are you going to go and just leave the place in this kind of mess?" He said, "Well, I think that we need to seize the opportunity and move on." And, "Yes, but you know, somebody's going to have to pick up these books here and what's going to happen then?" He said, "Well, I'll take care of them when I get up to Sacramento." And I said, "Oh, no!"

So he told me that he saw that as a stepping stone for disabled leadership to move on to greater things. I said, "But Ed, you know, those stones are us. You know, you don't step on

us to do that." That's when we had the big falling out and it was over that. Because I was just afraid that with him gone and with the folks that were left over there that they weren't going to be able to pull the rabbits out of the hat to keep the place afloat. And after that I became known as a CIL hater.
[laughs]

Breslin: You did?

Pachovas: Yes.

Breslin: Were you?

Pachovas: No.

Breslin: What do you think CIL did for the community here?

Pachovas: Put us on the map. Everybody thinks anything we do here is because CIL is here.

Breslin: What do you think about that?

Pachovas: Well, it's annoying sometimes. I wish they--you know, I wish--they had a greater sense of purpose. Whatever grant monies would keep the doors open. We started CIL up so there would be basically five things and we're not doing much of any of those anymore. Either other agencies are doing them, and not as well as we were, or they're not being done period. You know, we were doing advocacy, we were doing housing searches for people, we were finding them attendants, we were providing them with transportation, we were fixing their wheelchairs, and that was the basic core services and unfortunately for us we never got funded to do just that!

Breslin: When you say CIL, you refer to yourself as having been involved with the organization, at least sort of conceptually. What do you see your relationship to CIL as during those days. I mean, you were on the board at one point, but this was a little earlier I think. How did you think of yourself in relation to CIL then? I mean, it sounds like you have--

Pachovas: Well, they were more of a hindrance to my work than a help at the time and so I found that to be annoying. I just found the whole notion to be annoying more than CIL was doing it--

Breslin: The whole notion of--

Pachovas: That they would like want to impede other people doing things independently--you know--starting organizations, doing things

out in the community that weren't specifically under their umbrella. I mean, that was the big falling out. That was the big split because I just didn't think that it needed to happen. They saw that as taking something away from CIL. That that was bad.

Breslin: I want to actually revisit that in a few minutes, but lets move, if that's okay.

Pachovas: Sure. [tape interruption]

Life as a Student; Disabled Prisoners' Program, and Sex Therapist

Breslin: So tell me a little bit about what it was like being a student during the time you were a student.

Pachovas: Well, it was something to do while you were having life. We went there to go to school and in order to get an education. I knew that I had a goal after I got out of school, but while school was going on we were creating a civil rights movement and that was a lot more exciting.

For a lot of us it was go to class, go to jail, get out of jail, go to court, go to class, go organize, go to meetings, so there was certainly no lack of things that were going on. In addition, you know, some of us were starting to patch into more mainstream things that had nothing to do with disability. At that time, you know, the women's rights movement was kind of on full-tilt boogie, the Native American Indian movement on campus was happening, there was a purge of the radical criminologists at the crim school, I think we burned Wurster Hall down back then--no, no, they had just rebuilt it then and were afraid we were going to burn it down again. Well, we took that place over. I think it was over the crim department.

The Best Radical Teachers

Pachovas: We had some of the best radical teachers here at the university. One of the things I figured out early was, "I think I want to take courses from people that they don't want to teach here because they probably are saying something that the great institution doesn't want us to know about." So I

took courses from Tony Platt in criminology and Harry Edwards in sociology and--oh, my mind just went blank--Steve McElmore in Native American studies. People that were doing serious work in their fields and very aggressive radical work in their fields because I wanted to hear what they had to say.

I disagreed with a lot of it at the time. I thought they were much too radical. It isn't except for the gift of hindsight that I started realizing that they were more on target than I was and that a lot of the stuff they were saying, especially about institutions, were true. But it was only through experience that I was able to gain a perspective on how it fit together. You know, you'd get a little piece of this and a little piece of that and you hoped that you'd carry on the good stuff and be able to put it to use.

Then there were some other professors that weren't radical, but they taught me a lot of stuff. I had a great course in rational planning. That was one of the best things that I took as far as being able to figure out how to organize and carry through with something, no matter what it was and how to put in safeguards along the way to look to see if you were going in the right direction with it.

Breslin: Who taught it?

Pachovas: You know, my mind is going blank. He was one of my favorite--oh, Roger Montgomery. [laughs] At that time, I mean, that was just kind of a happenstance. I dropped one course and I took his course. I came into the course about six weeks late--you know, a sixteen-week course--and they allowed me in. And I ended up getting an A+ in there because he would let you argue with him.

He had a wonderful model for how to plan something, but you know, in my opinion it had some gaps and some holes that experience helped me, you know, didn't quite fit the model, so we argued that. There was this wonderful project that Bechtel was trying to do--excuse me--down in South America, where they were trying to forge a city out in the jungle. They were using a rational planning model. We argued about whether or not that would work. And I kept telling him, "No, you've got to have--." The big dissension that we had was whether or not you had to consider the political climate as a part of a rational plan. He insisted that you don't, that that's not rational, that's emotional and it has no place in a rational planning model. I insisted that if you didn't you were going to get into big trouble because you would go down the line not knowing what you were up against, and that people aren't rational. So

right at the end of the course, a bunch of Indians who weren't being paid by the locals went and sabotaged all the bulldozers and destroyed their project down in South America. So that was what my term paper was about.

Breslin: That's a great story.

Pachovas: Ha! It was fun.

Breslin: So when did you actually graduate from Cal?

Pachovas: '76.

Breslin: And you began--

Pachovas: In '72.

Campus Access Survey

Breslin: And what was next for you then?

Pachovas: Well, there were a lot of things going on with me while I was being a student other than a lot of the stuff that our community was doing.

I was participating while I was a student on putting together a whole plan to make the campus--the entire campus--accessible. So they were paying me to walk around with an architect, telling him which paths were and which paths weren't adequate. Which ones had too much cross slope. It was gut intuition at the time and not so much a measured science. What improvements needed to happen, what buildings needed to have access, all that kind of stuff. And it was wonderful. I got paid eight dollars an hour to go wander around campus during the spring. We did a survey of all the buildings and all the facilities. Then they started working out a whole plan to make them accessible.

Breslin: And what was the committee that was organizing that?

Pachovas: It was called the CCRAB committee, the Coordinating Committee for the Removal of Architectural Barriers. So we decided rather than banging heads--I guess the university decided more than we did--you know, rather than bang heads with them, that they should try to like pull us into the fold a bit and work together. That was very successful.

- Breslin: And that was a voluntary thing on the part of the university?
- Pachovas: Yes, it was. It was a collaboration between the Disabled Students' Union and the Disabled Students' Program and some of the architects and planners on campus.
- Breslin: And was that productive in terms of generating more access?
- Pachovas: Incredibly so, yes. I mean, we had the whole campus pretty much accessible in about five years from being maybe 10 percent accessible.
- Breslin: And how did that compare to other places that you knew about around the area, other campuses?
- Pachovas: It happened much faster. You know, after that there were laws that were passed that required that kind of work being done. Prior to '78 it wasn't happening.

Disabled Prisoners' Program in Vacaville

- Pachovas: I also started working with a group of people that were going up to--and this is where that rehab counselor story comes back --Karen Topp had a client who she did intake for up at Vacaville. He was imprisoned in the state in a California medical facility in Vacaville. She told us about that. We were just astounded that there were disabled people who lived in prisons, so a bunch of us in the community went up there and saw, "Whoa, this is not good!"

The conditions were very bad up there, so we started getting together to talk about going up there on a regular basis. Larry Biscamp was very instrumental in that. Esther Reynolds was. Who else was in there back in the old days? In the earlier days, Sid Fry. Let's see, Don Galloway was involved with us at a time, so was Dale Dahl. We had some very good counselors--Linda Barker--she was Linda Toms at the time--Mary Ellen O'Grady. We cycled through a lot of counselors.

One of the things that did happen--we had a very successful program working with these guys--and we decided that we would set up a formal independent living program within the confines of a total institution which was the prison to see what that kind of dichotomy would result in.

- Breslin: A contradictory--

Pachovas: Absolutely! Absolutely, you couldn't find a more contradictory situation than an independent living movement in a prison. It was great fun. It was dangerous, but it was great fun.

Breslin: Give me an example of how it worked.

Pachovas: Well, we would go up there, and we had offices up in some of the cell blocks that had been abandoned, and we would do intake on the prisoners who came in. They would tell us they were having this or that particular problem and some of it was just civil rights stuff--just flat out civil rights stuff. They weren't allowed into the work programs. they weren't allowed into the educational facilities, and because they were isolated in the medical wing they didn't have the same free run of the prison as did other people because an escort would have to take them from that wing to be able to participate in whatever they wanted to do. In order to make money, the only way they could make money--and I'm talking about nickels and dimes for things like milk--the only way they could make money at that time was to submit to medical experimentation.

Breslin: Really!

Pachovas: Yes, and so we set out to change some of that. Some of it, naively. Because I remember when I was trying to stop the medical experimentation stuff for an example, the reason there was a problem was some of the medical experimentation was in the form of a hot patch or a cold patch. Things as benign as cosmetic companies--you know, cold cream companies--would come and bring their cold cream and after animals and before people they would want to use prisoners. And they'd put, you know, cold cream on a certain spot and they'd put a gauze bandage over it and leave it on there for five days. They paid you \$1.25 a day if it was a cold patch, and something like \$2.75 if it might have been a hot patch. A hot patch was something that was thought maybe to be irritable to the skin, but still wasn't supposed to be something that they knew was irritable to the skin because they'd patched the animal with the thing. However, most of the people I had seen with patches had blistering, oozing sores coming down. The prison facilities were just horrible at the hospital--nobody ever wanted to go to the hospital--at the prison there.

One of the things that happened in the years that we were there is that we worked with the prison and opened up the educational classrooms, made them accessible to disabled people who wanted to go there who were prisoners. We also forced them to open up the shops and to put aside their prejudices and let people roll through there who wanted to make crafts and sell

them at the craft fairs or do things to make a little bit of money. So that they had other alternatives, because my first notion at that time was, "Well, we'll stop this medical experimentation crap," until one of my own clients pulled me aside and said, "Listen, don't fuck with our money." And I went, "Oh, yes, okay, a life lesson here. Okay, let's go about this differently." So what we did was open up more options to them.

As we grew with them, we started doing formal counseling. We hooked them up with rehab programs, we hooked them up with resources on the outside, and then did pre- and post-release planning with them and followed up once they got out. We tried to help them find a place to live, we would make sure that they got hooked up with rehab, that they got their SSI [Supplemental Security Income] if they were entitled to it, or whatever other kinds of benefits that were going on. Most of the programs up there at the time were not very favored by the administration, but ours over time became very favored. We were the only program--

Breslin: By the prison administration?

Pachovas: By the prison administration. We were the only program at one time that they told that had never been busted for carrying contraband in or out, which I found out later that one of our counselors was doing, but that's a different story.

I think that the reason it was successful was because when we weren't in there doing work, a lot of us were being arrested doing civil rights stuff. Some of us were running white water rivers, some of us were skydiving, some of us were doing things that nobody ever heard a disabled person do in their lives, and their notion about who they were changed because of that. Their notion about what we were as a group of people changed during those years. They started becoming more--I don't know what the word is that I want to use--but sort of more ennobled rather than pathetic and beaten down by the experience of a disability.

Then the people that we ran into fell in lots of different categories. Some of those people were not disabled people before they went into prison, but became disabled and then had to deal with being in a prison population and acquiring a disability that they knew nothing about or had any help with. Others became disabled just because of an adult onset disease. Others were disabled people who were bad guys that went out there--I had paraplegic cattle rustlers, quadriplegic rapists, I had one blind guy--they arrested him for sniping, but he went

in there and shot up the immigration office, just firing wildly, because they were deporting his wife to France and he was really angry. So it was kind of a testament to what the body can do. The human mind is incredibly capable of overcoming.

Breslin: So you got involved in this program when you were a student?

Pachovas: Yes.

Breslin: And stayed in it afterward?

Pachovas: Yes, we formally incorporated it, oh, 1977.

Breslin: And what was your relationship to the program?

Pachovas: Well, at first we were all counselors, and then I became the executive director.

Breslin: Were there other similar kinds of programs that you got involved with as a student that carried forward after you graduated?

Pachovas: Oh, I'd have to think. Well, the Berkeley Outreach Recreation Program [BORP]. I remember working all night one night with Lee Ann Kurtz and Susan Sygall to write that grant because it had to be in the next day. Geez, it was an awful thing.

The Disabled Students' Program and the Disabled Students' Unions popped up all over the state. I'm not sure which ones are still active and which ones aren't anymore, but the coalition went on and passed legislation that changed the way that all the community colleges and all the universities--at least in California at that time--had to deal with us as far as their admissions policies and their access policies. So a lot of those people really went on to help us get into other schools and colleges.

Then on the prison thing--unfortunately--it folded around 1983 because I stopped going there and didn't have a good enough sense to teach other people to learn what I had learned and have them feel empowered enough to carry on with the work.

Breslin: Did you team with any of the prison reform or prisoner rights organizations, or was that workable?

Pachovas: I'll tell you, it was spotty. It was spotty. I was working with John Maher from Delancey Street. We went over to Synanon.

Oh, I can't remember his last name now. They were working their own programs, but we were in this funny kind of situation where we had a disabled prisoner who couldn't get into their programs because their programs weren't accessible and we couldn't get him into nursing homes because nursing homes wouldn't take ex-felons, so we had a real situation in finding these people placements in the community.

But we were enormously successful in changing the rate of recidivism for the people that we followed up on. It was about 80 percent when we went in and we kept stats for about three years and our stats were 3 percent, so I think they caught on and then they went on.

Breslin: When was BORP founded?

Pachovas: When was BORP founded? [pause] Geez, somewhere between '74 and '76. I can't remember exactly which year.

Also in that time I was teaching school over at Cameron School for the Orthopedically Handicapped in El Cerrito. I went over there to be their psychologist and I ended up being their coach. So we started this--

Breslin: Sounds like a better office. [laughs]

Pachovas: Oh, it was so much fun! We started a wheelchair team that went down to the state championships and just kicked butt! It was one of the most fun things that I ever did in my life, was getting these Cameron roadrunners going. We had a wheelie exhibition team that came out of that, and we'd see the San Francisco children's film festival and perform and at CAL half-times and some of those kids really went on to do good things. Others of them actually are standing out panhandling on Shattuck Avenue, so you just kind of never know.

Breslin: That's a generational thing, I think.

Pachovas: But it was big fun. And then they closed down orthopedically handicapped schools because they'd mainstreamed them.

Breslin: Only closed down some of them. Um, you graduated in '77.

Pachovas: '76.

Breslin: And then what?

Training as a Socio-sexual Counselor/Educator

Pachovas: I got a grant from the National Institute of Mental Health to be one of the first ten people to be trained to be socio-sexual counselor educators at UC Med Center [University of California Medical Center] in San Francisco. So we went through a thousand hours of very intense hands-on training to be good sex therapists.

Breslin: As it were. Do it again. Socio-sexual--

Pachovas: Counselor/educator. It's socio-sexual and then counselor/educator. I don't know what they called us. We were sex counselors.

Breslin: And what kind of a program was this? Was this a degree program?

Pachovas: No, not at all. They had their own little funny accreditation. They gave you a little plaque and said you were one. We were the only ones in the field at that time, so it was just like this whole new budding thing. So they got a continuation grant and they taught thirty people altogether over a three-year period.

Breslin: And what did you do with your certification?

Pachovas: Well, immediately I was doing sex counselling on campus with disabled students and their families and spouses and others. And I was working at Crystal Springs Rehabilitation Center in San Mateo as the county human sexuality consultant. I worked as much with staff as I did with disabled people who were there. Then Prop. 13 came by and wiped out all new jobs, so I was off looking for something new to do.

California School of Professional Psychology

Pachovas: The next year I got accepted into the Ph.D. program at the California School of Professional Psychology here in Berkeley.

Breslin: And that's without having a master's degree? Did you go directly?

Pachovas: Right.

Breslin: And were you pursuing psychology because it interested you or were you pursuing it because you were sort of on a roll toward it?

Pachovas: That's a real good question. At that point in time? It seemed like the shortest goal, I think, to a career and to be able to be self-sustaining. I enjoyed it. Most of my area of interest in college was on dehumanization in institutionalized situations, so it was just a natural kind of thing. I'd been working in schools and prisons and, you know, different social institutions.

Breslin: And how was that experience?

Pachovas: Which one? [laughs]

Breslin: The California School for Professional Psychology?

Pachovas: It was very hard for me. It was very academic and I kind of enjoyed that, but my life was in total chaos and in flux at the time. In the middle of the school year I broke my back and so it knocked me out for most--for about sixteen weeks--at the end of the year. So I had to kind of limp through it all, not realizing I had a broken back until much later, so I was in pain a lot. I was going to school a lot.

At that time Ed made the change, Rehab was going to buy me a van so I could go to my placements, and then they decided not to. Also, the Feds decided that they weren't going to pay for my Ph.D., so I had \$10,000 worth of student loans and didn't know what I was going to do next, because I'd heard that they did pay for it when I started.

Breslin: This was the labor department?

Pachovas: Yes, the Department of Labor. As it turned out, they would have paid for a master's degree so they should have paid my student loan off, but they didn't.

Rivalries, Leadership Styles, Institutional Survival, and
Stumbling Blocks

Rivalry Within the Disabled Community

Breslin: So tell me a little bit about how you sort of remember the people in the community being able to get along with one another during this time.

Pachovas: There were intense rivalries that were going on. We were a community of people who by and large were not ego-less. Everybody just thought they had the right idea and the right hit on it, so we had a lot of differences of opinion. There was as much dissension over what was going on within the community as there was between us and the people we were trying to get our civil rights from, so it was kind of a microcosm for the larger society and what we were trying to struggle with.

I think that the way that we resolved it for the most part was to carve out our own niche and to be in our own little special areas. At that time, you know, thank God, I was a disabled student and so that was a natural link. I didn't have to get into whether I was going to speak or Ed was going to speak or, you know, somebody from the Disabled Women's Coalition was going to speak. It was an uneasy truce that we would show up.

There were lots of groups that did their own planning with each other. Everybody went and planned their own thing. As I might have said before, we all were eager to put our stamp on history and to say we did something--you know, we were of consequence--while we were here on Earth and that we weren't just a burden. I think that that motivated a lot of us. I think it still does. I think most of us are still underpaid for the work we do.

Breslin: So do you think there were legitimate political differences between people, people's perspectives?

Pachovas: Geez, what's a legitimate political difference? Hm, I think there were differences in style. I think there was a lot of competition for recognition. You know, I mean, it was kind of like we had gangs or something, kind of like the mafia.

Breslin: Like gangs?

Pachovas: Yes, it was kind of like when the mafia took over Chicago. They had to divvy up Chicago so they weren't shooting at each other all the time, and so I think that kind of happened to us. We got into our own little groups and our own organizations and we all had our own turf and we tried not to step on each other too hard. We did our own planning within our own little groups and then occasionally we tried to--you know, we yelled--"Hey, Rube," and tried to get everyone to come running. For the most part we achieved that. We were able to do that and so there was an uneasy truce because we did still retain that sense of a higher purpose that there was a bigger enemy than we were to each other. To the extent that we were able to keep our eye on the prize, we were able to just keep moving along.

Again, I think there were a lot of times when we were just our own stumbling blocks, you know, when we won't or can't work with someone. When I worked on putting together the Disabled American Freedom Rally in 1981, I was concerned that we weren't going to do anything of significance except for have dog and pony shows. The previous year had been the year of the disabled child and during that year they dismantled all the children's programs and defunded them. I thought, "Oh, Lord, and here comes us, and here comes [Ronald] Reagan!"

So I wanted us to do something that was helpful, but I recognized that by that point in our development that we were a bunch of communities and not really--you know--and not really a movement. I'm not sure that in some ways that I feel that we're closer now, not really a movement in the sense of one common purpose. However, I thought that if we could get together and just go do something as a group of people and get something that we could share in common, that we might be able to pull something off that was helpful.

So what we focused on was the Graham Lata amendment which was one of Congress's first attempts at slashing social programs across the board. They wanted to cut social programs by 20 percent clear across the board to save money. Reagan was coming in.

Breslin: Michael, tell me a little bit about your thoughts and observations about people's leadership style during sort of this period during the seventies when you were a student and making the transition into graduate school and doing other things.

Cult of Personality

Pachovas: Well, I'll tell you, it was all over the board. Most of the stuff--most of the [pause] styles of leadership--I think, did then and probably still do, probably revolve around a cult of personality. People who had strong charisma tended to attract loyal and disloyal followings for whatever reason. I think that it was almost the people right behind them that more molded who they were than they themselves, because it pushed them in different directions and made for some interesting dramas.

You know, some of us knew that we wanted to be a part of the disability civil rights movement, work in it, and be a part of it forever and ever and that was our life and if we could make a living out of it, so much the better. And others didn't. They felt like they wanted to participate in something or have something happen and then go do something different or move on.

There was so much to do. It was like a smorgasbord in front of me. When there's such overwhelming need in so many different areas, it's real easy to carve out a little area and make a niche for yourself. Fortunately for those of us who grew up then, we had a resume in a year or two that looked pretty respectable, you know, compared to other social movements. So it wasn't hard to move not only within the movement from place to place, or organization to organization, or issue to issue, but it was pretty easy to move horizontally, as well, between disability and other kinds of social movements--the women's movement, all kinds of different things that were going on, the American Indian movement that was going on at that time. Oh, preservation, you know, historical preservation, you could carve a niche out into a lot of different areas. You were respected because your past experience had told people that you had had a successful track record of doing good work and represented--for lack of anyone else being there, maybe--a community and their participation in whatever interest area that you had.

Negative Impact of Growth

Pachovas: For me, I think that I'm more interested in projects. I've seen what happens with our institutions, and I don't have the answer to how to not have that happen. I don't know what the

answer is to not have an institution grow larger than the movement and then stifle it in significant ways. I think I understand it fairly well, but I don't know what the good answer is to fixing it.

I know that you start out one day and you're all comrades. Then you try to get something done and you actually succeed in doing it. And that's kind of cool. Then you try to make sure that there's a permanent patch there and a permanent fix, and it wasn't just a one-time only thing. So what happens is you hit the headlights and you get on Donahue and Sally Jesse [Raphael] and all those shows and you're the sexy thing at the moment and they give you some money to try to solve the problem. So what you do is you start a group or an agency or an organization to try to work in that area and to try to solve that problem on a lasting basis. So you get in there and well, you know, whether you recognize it or not, you've formed an institution. Institutions are meant to be enduring. That's one of the hallmarks of an institution, is it's meant to endure.

However, I think that to our detriment and to all the movements' detriments what happens is that it's very difficult to maintain the mission for the institution that got formed when confronted with basic things like survival--survival of the institution--when all of a sudden you're there and you start to grow and then there a lot of other things that happen in different ways. For example, you can start to grow and then all of a sudden you've grown so big that you have to departmentalize to be able to do as many things as you're doing. So you start getting, you know, department heads, and you start getting receptionists, and you start getting, you know, even complaint departments. We even institutionalize complaining about it. All of those things have a certain amount of impact and import, but they aren't things that are necessarily good or bad for the community. It does set kind of another layer between the people you're serving and who makes the decisions.

I mean, let's say we form an institution to, oh, want to better educate our children. We go in there and there's a receptionist there and you have to deal with the receptionist and set up an appointment. You pass the receptionist and you don't like what's going on. They have somebody who's an ombudsperson, and you deal with the ombudsperson about what's going on with your kid or whatever. Then it's a legitimate thing and you try to push it up to the department where it's being dealt with. Maybe the department head will get involved in it and that department head reports what's going on to the

director or to whatever layer that's between him and the director, specifically. Then the director, of course, is responsible to the board of directors. He's got a lot of stuff to do.

By the time your complaint gets to where people are making policy differences there's a lot of layers--different interpretations--about what the issues are. There are a lot of restrictions that you, who brought the complaint, aren't aware of. And you have no idea that they don't have the funds to do the kinds of changes that you want when you walk in the door. You would think that it would be somewhat easier, or that they have other priorities, or they have other needs that exist that have nothing to do with what that mission is--that they need to go out and do fund-raisers, and shake hands, and kiss babies, and warm up the politicians, and go to conferences, and spread the notion around, and do a bunch of other stuff that's other than teaching my kid how to write, you know, or something like that.

It's a necessary thing. If you're going to form an institution, you've got to do stuff to keep it alive. I know that we all believe that without an institution the place would fall apart and go to hell and we'd have nothing. I think that's the great myth that we buy into.

Shift in Priorities

Breslin: Well, do you think that the institutions that got built in the seventies in Berkeley and notably the Disabled Students' Program and CIL, the early organizations, and BORP--certainly--that have had a very early and long history, have they served the community well or badly?

Pachovas: Both. And I have to be somewhat qualified in how I say that. Let's look at those three examples.

The Disabled Students' Union served its purpose well for the reason that it began, which was to give the students a voice on campus. However, things changed. Over the years what happened was when there were student issues then students would get together and the disabled students union would be strong. But with changes in the directorship and changes of students coming in and an institutional change and the type of student that was coming in, those complaints diminished and the problems became less. And as the institution that was supposed

to serve their needs, for example, the disabled students program, got better at what they were doing and served those needs, there weren't as many complaints. So they kind of went hand and hand. There was an institutional development on the issue to deal with the problem then there was a direct response by the agency that was supposed to solve it. So after a time what happened with the Disabled Students' Union is that as new students came in and less students complained, less and less students got involved in things, for whatever reason. And I'm not sure if it even exists today or not, or whether they just get together when they need to do something.

At the Center for Independent Living--

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Breslin: I'm sorry Michael, go ahead with your thought.

Pachovas: No, I was just saying for example--I don't want to pick on CIL in any way--but they're a good example of what happens to a lot of the movement and the institutions that we create to fix our problem, and that is that you grow. I'm going to leave all the personality stuff aside, because that's a huge scene all of its own. There's lots of little psycho-dramas that go on that create things the way they do. But assuming there's none, assuming it's just an institutional thing, what happens is you grow and sometimes you grow too big. And you start, as I said, again, going through the whole compartmentalization, departmentalization, and forming layers between you and the people you serve. It's an inevitable thing because you have a lot of people and you've got to figure out some hierarchal structure so that you can get your work done.

The director's going to be on the hot seat for whatever happens at that agency when he goes to the board of directors. Now, the board of directors during that period of time changes. It's not just the guys that are being served any more. They want some people that are going to bring some power and prestige and money and talent into the organization. They're going to stop getting so many quote "just disabled people." "Geez, this guy heads this foundation, let's put him on our board because he can bring in some lasting resources. This person is the mayor and so let's put them on the board because they can bring us some political muscle if we need it." Well, there are so many seats on the board and after a period of time what can happen is you become less and less directly responsible to the people you serve. You don't replace that mechanism with something that's either as powerful or as

direct. You have a lot of people now on the board that have different orientations to what you're doing.

So here you are--some schmuck on the outside--and all you know is all of a sudden they're not doing wheelchair repair any more. You don't know why and you don't know that it's because they're not getting paid any more to do wheelchair repair. Well, somebody else came on Jerry and Sally's shows and Geraldo's show and they had to deal with these damn baby harp seals. America loves these baby harp seals. All of a sudden we're old news and all that easy money starts getting harder to get because they have to have some of the money for the baby harp seals and not quite as much money for us. This is not as sexy. And people go on and they do their thing on the baby harp seals and get their press and do all that stuff that kept the money flowing in.

We start looking for, "Well, how we're going to keep this thing afloat? We still have this mission for serving these needs. Well, you know, what we can do is there are other areas of interest."

Because now, once you're around long enough, the academic community gets hold of you and decide that they have some areas within their specialty, that are of interest to them they would like to study your little subculture as a part of it. So we'll get things like, you know, I&E [innovation and expansion] monies to do special projects for the Department of Rehabilitation that aren't specifically fixing a wheelchair, getting you an attendant, or doing those things that we started out for, but have enough overhead in there that if we can push that 25 percent or 20 percent over, then we can use that to fund core services.

At some point during that development, you're doing more of the second than you were the first because you have to do the grants, you have to commit, and you have to do the programs, and you're bringing in new people to do those things because they have some special area of interest that you know about, and the whole structure of the place starts to change.

There's new faces that show up. There are new places. There are new people who don't know why you were here to begin with, but they're working on their project. It gets a little less and less focussed on the specific mission that the thing was started up to do.

Now, that in itself isn't a bad thing, but it is a thing that we have to deal with because it may be good that we're

dealing with how to get children educated and that we're dealing with how to make sure that our health care is taken care of, but you know, it's a different priority.

Original Issues No Longer Addressed

Pachovas: The ones that we had are not now being addressed. They aren't being addressed for a number of reasons. One is because there's this common belief that if the institution that was organized to address that problem exists then it must be doing its job. Then that institution becomes a stumbling block; it becomes a barrier to someone out in the community says who says, "Hey! I need to get picked up if I'm stuck in the street. That's not happening. What do I do about that?"

Well, everybody assumes in this case you'd call CIL. Well, CIL stopped doing that a long time ago, but you know, people still don't realize that. If you ask the average Berkeley person--well, not only if there is a CIL, and a lot of them don't know that--but what they do and you laid out a whole list of things, they would probably assume they were doing the basic core stuff, so when that's not happening, now you've got a problem.

Now you've got a problem. You're trying to figure out, "Well, shit, you know, what do I do? I don't want to say that we can't take care of our own business. That would be bad, because we don't want people thinking we can't take care of our own business, even if we can't, so we better just shut up about it. We could go to the complaint department, but then if I go to the complaint department and I have to do it more than once, they're going to call me a whiner and they're going to discredit what my complaint is."

Organizations have a nice way of kind of doing that. It's a subtle kind of thing where you become one of the whiners or you become an outsider, or you become one of the disenfranchised, or whatever it is, and not dealing specifically with the issues that you bring up. It's more and more you as a person and they personalize it. And they can't fix it.

You know, no way they can't fix it, but it's a good defense mechanism. And you're way removed by this time from the board of directors. I mean, your comments are now chairman this, department head this, and staff person this, and the secretary.

And they're not George and Sam and Tim and CeCe. You've lost touch with that.

So you've got to make a decision: "Well, what do I do? Do I say nothing about it? Do I continue to complain--take it up through the ranks--get it up to the board of directors who really don't know, or who have a different perspective on what we should be doing but aren't resolving this one? Or do I start something new? And if I have to start something new, well, guess what, there's this perception that the old agency is doing it, so why do we have to have something new doing it?"

That's the rub. That's the rub. That's the big problem. It is then the institution becomes a stumbling block. Einstein said something about the notion of truth one time in the academic community and said that--so, really loosely translated--that basically when the academic community seizes upon a notion that it believes to be the truth with a capital T, it loves that, it just loves it. When just absolutely irrefutable evidence to the contrary comes by, it becomes very difficult for that to be established because there already is a truth in place. I think we do the same things with our social institutions. We'll create an institution like a school or a church and everybody thinks they're turning out good Christians; they're turning out good educated children; and man, aren't we surprised when we read in the papers that the kids aren't being educated and the Christians are out, you know, burning black people on crosses and doing all kinds of things that are surprising to us. And we don't know how they got that way.

So we have to be careful. We have to be careful, you know, when we set up these institutions to acknowledge that they can change. They can change for a variety of different reasons that are way beyond any of our control.

I think part of it is just because that's how all of society works. As you get one institution that has certain parameters, and they can only do certain things and they want to stay in the fold, or they can just discount it and that handcuffs us. As I was saying earlier, an institution can't go over to the mayor's house and do a sit-in on the lawn, not without risk of losing their funds. I mean, maybe ours. We may be one of the few that can, okay?

Breslin: [light laughter] Well, we used to be able to. I don't know if we maybe still can.

Pachovas: We still kind of do. But you know, in general, you're not going to see the art society or the board of education going over there and sitting on the governor's lawn very often.

Breslin: Well, this is an interesting set of observations about leadership and organizations generally. Let me just ask you one more question because it's on my mind and kind of flows from that set of observations. The movement as we define it in this area is predominantly made up of people with physical disabilities most of whom are white, most of whom--I mean, there's an age spread--but we're talking about the folks that are predominantly younger rather than seniors, for example. How do you account for the fact that there's so little racial diversity in our movement and in our leadership?

Pachovas: I think that some of it's economic and I think that some of it's demographic. I think that you have a lot of quadriplegics who got hurt doing recreational activities that kids in the inner city don't have advantage of. I mean, how many people do we know that you know broke their necks on a trampoline or a motorcycle, or you know skiing and things like that? Whereas a lot of their people how have no access to those activities, wouldn't even be participating. So I think that's a chunk of it. In addition, we're surviving. We're surviving. You know, you get hurt here, right near UC Med or at what's the rehab down here in San Jose?

Breslin: Santa Clara Valley [Medical Center]?

Pachovas: Yes, Santa Clara Valley Med--you're going to have a lot better chance of surviving it than if you're, you know--down in the rural South and getting into it and getting into a rehab facility. So I think that some of it's economic and some of it's demographic.

We still have a basically--it's not even bifurcated--but it's, you know, a split-up society, in which we tend to stay to our own. I think that the racial differences in America have grown rather than lessened. I think that the black community tends to stay to itself more than it used to and not be clamoring as much for inclusion in the way that the Indians were back then. We had a difference back then between being assimilated into a society versus having a society want to be able to appreciate your own specific diversity and not discriminate against that. We don't relish cultural diversity here. I mean, we're white guys, we know white things, we do white things, we hang out with white guys; or you know, we're not.

You know, we're going to learn--you know, we're going to go stay on the reservation or we're not, or we're going to do things to help get Native land claims together. We're going to do things that bring us back to our ethnic roots because there are too many of us dying off and so many of us have intermarried that our race is kind of losing out. So there's a lot of getting back to the roots and wanting to maintain your cultural identity. I think that we're in a time of that and that's probably greater than any other time now.

Why, I'm not sure. Partially I think it's maybe for the same reasons we got together the disabled community way back then--that we had some common issues--and we tended to seek each other out for affinity. So I think there's a lot of that and that there's less, less, barrier crossing than there used to be.

Now, there might be in this institutional stuff, where you have to look good in the box course--you have to hire X number of minorities, you know, within your group or your organization or whatever--yes, you know, that pushes it along. But still, my sense about it is that we're not doing that. We don't know who these people are.

Let's look at our own community. I mean, we know maybe a dozen black people here in Berkeley, or more, if you're lucky. But how many black people are here in Berkeley who have a disability? We don't know. We have no idea. We don't hang out with them, they don't come to our meetings, we don't go to their meetings if they had meetings, and they're usually people that aren't very well off economically. And because of our mobility it's really hard to be represented.

The same thing was true early--especially in the earlier years--for quadriplegics. When I joined the NPF [National Paraplegic Foundation] way back in the early seventies, hey, I went to a conference and I didn't see any other quadriplegics there. There were a lot of paraplegics and a lot of white guys, you know, in wheelchairs, but there sure weren't many quads. And they were making environmental changes and they weren't in my best interests. So you see that.

In another sort of way--I mean, let's look at the blind community for an example, and the visual impairment versus the rest of the disability community and them wanting to carve out kind of their own niche in being sensory impaired or sensory disabled versus a physical disability. Yet it may be a physical cause that creates the blindness, but it's a semantic thing and it's a truth thing. They've worked out their own

thing, and they've been around for a long time, thank you. They don't want to be co-opted by some upstart new movement coming in. They have their own sort of, you know, their own little mafia going on that they feel at least reasonably comfortable with maintaining, at least not enough to break out of it.

And even within our groups, you have the National Federation of the Blind, you have the American Council of the Blind. They don't agree on a lot of things: should we have help? Should we not have help? You know? That's one of the major issues. So we have these kinds of differences for lots of different reasons.

Breslin: Okay, let's stop at that point, but let's pick it up next time talking about what you remember of the late seventies and sort of what your role was in relation to the HEW [Department of Health, Education and Welfare] Title IV sit-in and things beyond that. Okay?

Pachovas: Okay.

Breslin: Terrific. Thanks.

III TWENTY-SIX YEARS OF POLITICAL ACTIVISM AND THOUGHTS ON FUTURE CHALLENGES

[Interview 3: September 1, 1998] ##

Chained to a Rock for Ten Days, Saving Wild and Scenic Rivers, 1981

Breslin: Michael, we sort of ended the last time talking about institutions and organizations that have come from the disability movement in the Berkeley area. Let's talk about your recollections of some key events in your life in the 1980s. You were involved in the Stanislaus Wilderness Action Committee--is that an important landmark for you?

Pachovas: Well, it was one of the more defining ones as far as my involvement with things that transcended just the inter-disability community kinds of activities. In that instance, we were working specifically to try to save the Stanislaus River from being inundated by a giant reservoir, and at the same time, try to figure out what we could do about saving some of the other California rivers that were being scheduled for massive dam projects.

We had been working during the previous two years with other groups like Friends of the River and some of those folks to try to think about what we might be able to do to bring public light to bear on the situation with rivers all over the country being dammed up by the Army Corps of Engineers. We felt that this was a time of transition from the Carter Administration to what was likely to be a Republican reign.

Breslin: What year was this?

Pachovas: This was just in late 1980. After working with some of the folks who had been working in more mainstream environmental movements--many of us at that time were doing rafting. We were rafters. I used to go rafting with Mark Sutton, you know, who

was blind. I actually trusted Mark to row for me better than I did able-bodied people.

Breslin: Why?

Pachovas: Well, because able-bodied people would tend to second guess what I was trying to ask them to do. I ended up in the river about three or four times with able-bodied folks rowing, and never with Mark rowing. I can read rivers really well; I can't row worth a damn. Mark can't see, so it worked out really well and we had a good trusting relationship. Bob Metts and Dennis Fantin had kind of pioneered that whole buddy system, and we picked up from where they were, so we used to go rafting a lot together.

Breslin: Just stop for a minute and tell me who Bob Metts and Dennis Fantin are in the context of your personal life and Berkeley movement.

Pachovas: Well, Bob Metts is a very iconoclastic, ascerbic, disabled person who went to Cal and got his Ph.D. in economics and immediately preceded me, I believe, in being enrolled at the university. Dennis Fantin, likewise, had been going to the University of California prior to Bob. I don't know why I think Dennis' major was math, but I know he works a lot with computers, and I can't recall what his major was. But they are both very, very bright, very articulate disabled people, who I came into friendship with largely because we all liked to go rafting. So although they were kind of a bit more of the old order, you know, from my perspective, that was one of those times when the marriages between the older and the new wave that came through worked out very well.

We went on a lot of rafting trips together. [laughs] And some of them pretty hysterical. We all got together. I think that our common denominators were that we respected each other's political opinions. Bob Metts, prior to that, assumed the leadership of the Disabled Students' Union at the University of California. They had a coup and threw out an old group of people who were the officers and brought in a new group. We're talking a lot about moving and the transition from the Cowell program into the dormitories. Well, we had an office up at Eshelman, up on the fifth floor, I guess, of Eshelman Hall, which was the student union building. From there we were able to do a lot of different creative projects.

Stanislaus Wilderness Action Committee

Pachovas: One of them being the Stanislaus Wilderness Action Committee, or Access Committee, depending on who we were talking to at the time, or if they were trying to raise any money for what we were doing. You know, my mind went blank. I don't know why my mind goes blank on this, the activists. my mind is a blank.

We had talked to one of the activists who had first chained himself to a river and thought that might be a good idea, because it would bring some publicity.

Breslin: This was an environmentalist?

Pachovas: Yes, and I don't know why I'm blanking on his name. I know him very well, he's a friend. But at any rate, he did that and it brought considerable attention to the plight of the rivers. It was a good shot and it missed. Nobody really picked up after that, so I don't know why it struck us that it would be a good idea if we all tried to do it. But it struck me at the time, that, you know, I think people aren't understanding that this river means a lot to our community, and that it might be helpful to use the charisma that we had in our community to be able to extend that to other causes.

Breslin: You mean the charisma of the disability community?

Pachovas: Right. We were still hot at that time, on this sexy issue. So what we decided was that we would do political lobbying and organizing and try to save that river and figure out if we could extend that to anything else. Originally the plan was that Dave--um, well, what's his name; I'm just bad on names today. Anyway, originally I was going to be working in the office dealing with some press relations. We had a wonderful press man working with us and I've just forgotten his name. Dennis and Bob and I all had different functions in trying to figure out how to put pressure on Congress and on the state legislature if we were going to do something really dramatic.

Breslin: What was the goal?

Pachovas: The goal was to try, first, to stop them from flooding the Stanislaus River, and second, to stop the Army Corps of Engineers from coming in and tearing up all of our rivers. It was hard to do that because they claimed that the Feds had, you know, authority to do whatever they want. What was going on in the background behind that was Tony Coelho, who is still this, "great friend of the disabled community," and who was the chief

fundraiser for the Democratic party at the time, was basically getting his buddies to buy up lots of land around rivers all over California that were scheduled by his committee to be dammed up. These friends would buy lots of land and then all of a sudden there would be a public announcement that a dam and a reservoir were going to be built there. The feds would have to come in and buy up all the land that his friends had bought at wildly inflated prices. So they did that, over and over and over again, and started building many, many reservoirs in the Sierra foothills.

We were trying to tell the press that this was going on. People weren't really willing to listen to it, too much. We knew that. And of course, when his friends did get paid off for the land, they made large contributions to the Democratic Party, so we didn't have a lot of political power with the Carter Administration. We also knew, again, that Carter was leaving and we knew that Reagan was coming in, because it had gotten late 1980, the elections were over.

Reagan was coming in, and we really feared that anything environmental would be lost if we didn't take immediate action. We thought our best shot was trying to do something while Carter was still in office. He had had such a terrible time at the time that our opinion was that there were two ways that he was going to go. He had to do something to try to salvage something of his legacy as a president. And we thought that one of two things might happen: one, he was either going to figure out how to get the hostages out of Iran, or two, he might do something that would help preserve some of the California rivers and some of the other rivers that were being dammed up because it was an item that the Sierra Club and a number of other organizations had been lobbying him to do.

Public Relations Vigil

Pachovas: Well, it struck us that we needed to dramatize the situation, so initially Mark Beckwith, another very disabled person in the community whose been politically active for a lot of years, was going to be our person to go up with Rick Spitler and Kale-- like I said today, I'm having trouble remembering names. Well, Kale--and chain himself to a boulder near the river, so that if the reservoir rose, literally they would be risking drowning. Now the joke was that he would die of hypothermia much faster than he would have died of drowning, but nonetheless, that was the image that we portrayed.

At the last minute, though, it got very, very cold--it was the first week of January up in the Sierras--and we made a last minute decision that we shouldn't send him up there, but we should send me, because my constitution was stronger. Mark had a very hard time breathing and had upper respiratory complications that I didn't have at the time. So we made a last minute switch. Literally a last minute switch.

I mean, we decided that we would send Kale, and Rick and I up and then orchestrate through--okay, now I've got Don's first name--through Don, a whole public relations campaign to try to get the president to save this river and to try to push the state legislature into putting together a Wild and Scenic River act that had some teeth behind it. We wanted the state legislature, at that time, to tell the federal government that they had to get permission of the states before they could build dams in any particular state. The state legislature was mixed about it.

We thought that we would be up there for at a maximum of three days, that it would either work or it wouldn't work and that we would be out of there. So we packed ourselves up with lots of sleeping bags and things that would keep us warm, and a little air mattress that I could sit on. And the folks ahead of us paddled up and dug out an embankment into the ground just above the water level, just below where the dam was going to be. It was a very densely wooded area, so it was very hard to find us. And then they also proceeded to build kind of a rabbit warren out of sticks and twigs and branches and all that to make it very similar to the brush and the surrounding hillside. The notion was that they would paddle me up in the middle of the night and we would all go sit there and [I would] chain myself, of course, to them and then to a boulder and send the keys to the White House.

So we did that. We went up in the middle of the night. At three o'clock in the morning we were driving down these roads that are full of people and signs saying, "Stay out of here," and, "No rafters allowed," you know, "Private Property," and all this stuff. We put in the water and paddled up to where we were going and found ourselves on this little shelf that we had dug out, and then they proceeded to build the rabbit warren out of the branches that they had collected at the site and built a literal cage around us.

Now that was helped, somewhat, by a bunch of the women that were up there who had dyed a lot of sheets the same color as the surrounding earth. We figured that, if it was successful or not, they would probably be looking for us. We wanted to be

able to hide as best we could because there were a lot of people that were very hostile up there to our intent. Especially people who had been told that they were going to own land on a very wealthy reservoir and be able to bring some business into the area.

So we did that. We went up there and we chained ourselves in. We built the rabbit warren around us. And I made them drag the wheelchair--

Breslin: Your power chair?

Pachovas: My push chair. No, my push chair up there. We couldn't get the power chair up there because it's just on a shelf, but we wanted the push chair up there, because we knew that if we could turn it into a press spectacle, the symbol of the wheelchair being there would be very important to us.

It was kind of an amazing experience. It was so cold. The first three days we were there, we couldn't communicate very well with what was going on. I did have a small radio with me at the time, so we could tell if we were making any news. Strangely enough we were. And then after a couple of days, all of a sudden we started--we would get--one of the kayakers would paddle up in the middle of the night and tell us what was happening and bring us food and things like that. We couldn't build a fire. We couldn't have anything warm because it could be seen, so we knew that we had to just eat cold food and stay bundled up. For about three days we just stayed bundled up. We started hearing that what we were doing was successful and we were advised to stay longer, which none of us wanted to do. [laughter] And they couldn't give us a call on whether this was being successful or not successful, so we didn't know whether to go home and get warm, or just continue to stay.

Bob went to a second site with one of the women up on the river, so there were three of us in my thing, two of us on a second site. After a few days, for whatever reason, and I can't remember what it was, Bob had to leave that site. It might have been the conditions.

Well, we were being advised, by Dennis mostly, who was kind of running the show back home, that what we were doing was being very successful and that there were lots of rumors flying around about whether we were really up there or not, and so he got Don to choreograph some press coming up. So they got some of the major news shows--"Good Morning America," all those kinds of shows--to send crews out that we would smuggle up onto the river in the middle of the night.

So here are all these news crews that were bidding with Don--literally bidding--for how much air coverage they'd give us if they could go first and get the hell out of there. So depending on what kind of coverage they'd give us in the next day's news, Don made decisions about who came up and interviewed us first. They would come up with all their camera stuff and had to literally climb through this little kind of cave of bramble to get to us and then interview us and see that, yes, we were really there and no, it wasn't just a stunt, and yes, we were chained up and that we were serious about what we were going to do.

Well, the days stretched on. This became big press. One of the running battles that kept happening was that as we were up there, more and more people got into lobbying the president. So wherever the president went during those last few days of January, the Sierra Club, Friends of the River, everyone else, and now, disability community activists, started besieging him to do something about the situation. They knew that if they turned the water on, that they would drown us. They didn't want that to happen and we were convincing that we were going to stay there if they did that.

Response from the White House

Breslin: Was there any response from the White House?

Pachovas: Lots of it, lots of it, and that's what made the fun news. Tony Coelho would talk about how irresponsible we were, there were political cartoons in the local paper showing us to be a bunch of hippies standing in shallow water, there were lots of funny things going on at the time. Coelho would say, "It's not an issue at the White House," so the press would paddle up and they'd tell us that Coelho says it's not an issue at the White House, "What do you think?" We were pretty frank about it. I said, "Well, Coelho's been a liar before, and I guess I'd have to say he's being a liar now."

So armed with that, they would go back to their radios and trucks and TV cameras and then have their people in Washington contact the president, find out whether it was or was not a dead issue. The press secretary would say, "Oh, no, this is definitely a major issue with the president and he's carefully considering it." The next day the papers would say, "Coelho Lies," and give us great joy. We were very frank about what was in it for Coelho.

Now, shortly after that, about a year, a year and a half after that, was an investigation into his fundraising and he resigned from Congress, so we did get some after the fact joy from that.

But the three days stretched into ten days and it was very unpleasant for most of the time. What my major concern at the time, because now it started to warm a little bit, was that it was going to rain. If it rained, it would wash us into the reservoir. The thunderclouds were looking pretty ominous, so I suggested on a few occasions that we dig a trench around the back side of us, so the water could divert. And it's kind of, "Okay, yes, well, we'll think about it and it'll be maybe later."

We ended up eating a lot of cake. I don't know why people didn't give us regular food, but everybody baked us cakes and cookies. [laughter] I never ate so much cake and cookies in my whole life. And we were grateful for--

Breslin: Probably happy to have the two major food groups represented.

Pachovas: It was amazing how simple pleasures, like a can of tuna, can really brighten up an otherwise dreary life. Now, Jerry Brown had gotten into the act and got the legislature to support his taking a bill, by hand, to Washington to lobby the president to try to pass the National Wild and Scenic Rivers Act. So he went off to Washington. Every day as we were getting colder, we were getting word that what we were doing was very successful and that we should stay put. So they were doing all this lobbying in the background.

On the tenth day that we were up there, and it was cold-- and then the worst thing that happened physically is that Kale punched a knife through a pie pan and stuck it into the air mattress that I was sitting in--depriving me of any way of not hurting when I sat on the ground. So we were trying to do lots of little funny patches, trying to keep the air in, but mostly having to repump this thing up many times a day. And I started developing a bit of a kidney infection because we just weren't drinking enough.

Breslin: Yes.

Pachovas: We couldn't have warm water and the cold water was just unpalatable on a really cold day, but nonetheless, we held out. It was sort of intrepid.

Dan Ellsberg decided that he was going to do this big vigil in San Francisco for us and bring more light to bear on this whole situation. The one thing that we didn't anticipate because none of us was so-minded, was that it was the opening of duck season. We hadn't thought of that. [laughter] So it was legal for anybody who was mad about what we were doing to go riding around with a shotgun looking for us, which they did.

Breslin: Sitting ducks, as it were.

Pachovas: We were. It was amazing, because at one point, about on the ninth day, I remember waking up and hearing--and we got used to talking really quietly because your voice would just boom across the canyon. We'd hear this, "Quack, quack, quack--quack, quack, quack--quack, quack, quack." Now, the previous day people had ridden by in boats, calling us out by name, just wondering if we would respond. We just stayed hidden. Everybody was looking for us: the sheriff and the police. And, well, the idiots were looking on the wrong side of the dam. They were looking up river, on the river part of it, and we were down below where the dam was, so it was kind of this exercise in stupidity. But every once in a while surveillance planes and things would fly by and we'd cover everything up with the earth covered stuff and try to make ourselves as inconspicuous as possible and be still so no one could find us. There was this massive search to try to find us. As I said, the previous day, people had been trying to call us out, saying it was okay to come out, and when we peeked out we saw there were men in boats with guns, so we didn't want to do that.

Breslin: No, right.

Pachovas: The next morning--the morning of the tenth morning that we were there--we heard, "Quack, quack, quack," and Rick kind of looked over to me and mouthed, "Duck." I shook my head and said, "No, duck hunter," you know. Sure enough, we kind of peeped out from our little sheets and there were some guys in boats with guns and so we just stayed kind of quiet again and let them pass. The clouds started getting really ominous. I kept saying, "You know, we better dig a trench. This is not going to be good for us."

We didn't dig a trench. We were told just about then that they had worked out whatever deal they could work out in Washington and that we should get off the river and we should come home. So we got ready to leave and it started to rain just as we were leaving. It was just a very opportune timing. So we got out of there and started heading back toward camp and tried to figure out what we were supposed to do next, because

we were sort of out of touch up there with what was happening back at the office.

Well, one of the folks had told us that there was this vigil that they were holding in San Francisco that night for us, so we decided to go. So here we went to this candlelight vigil over in San Francisco, you know, at U.N. Plaza. They were doing all this embarrassing kind of talking about how heroic we were, and we were just like these cold guys in the mud, you know, and smelling like bears, and it was just awful up there. So we showed up at our own vigil, which was kind of surprising to everyone. We really were grimy. So we talked about our experiences and everybody loved the whole notion.

Victorious End to Vigil

Pachovas: What we found out was that the deal they had cut was that they were going to go ahead and flood the Stanislaus River, but Congress was going to pass the Wild and Scenic River Act and the president was going to sign it. So they did sign the Wild and Scenic River Act which saved, I think, nine other California rivers that were slated for dam projects--six or nine--I can't remember the exact number. It established the rule that the federal government could no longer go in just because it wanted to and build a dam somewhere, that they had to have the consent of the state legislature to do that. So for whatever good that did, it did us some good here in California, anyway. Then we went on to other things, basically.

Breslin: Well, what do you think the impact of the expertise from the disability community had on the outcome?

Pachovas: It had a lot. I think not just because we were disabled, but that symbol was very helpful, for one thing.

Breslin: Why?

Pachovas: Because it piqued public sympathy and curiosity. It did a lot of different things. Number one, it made a lot of people aware that disabled people went rafting. They never even thought that that was something capable of us doing. That's a bad sentence, but anyway--that we were capable of doing. So that struck their fancy. The image of the wheelchair sitting there ran in every major paper in the country. Us sitting in the mud, chained up there, really sold this story. So I think the

image of our being up there really helped the environmental community sell this story. That this was our river that we used for training disabled people to raft was very important to the story and I think without us being there and the obvious symbol of the wheelchair, it wouldn't have gone anywhere. So I think, to that extent, that it was very helpful.

Some people said, Well, you just used your disability. Well, you know what, if that's how we use our disability, I think, fine, fine, then let's do that. We learned from our experience as being disabled activists how to get the public interest in what you're doing. We had become very good at organizing media campaigns and I think that was very helpful to what was happening then.

Breslin: What do you think the outcome would have been if you hadn't done that action?

Pachovas: I think that they would have just gone on and completed all the dam projects that they had scheduled and flooded a bunch of rivers, and they would continue doing it. We would have lost a lot of the wild, scenic rivers here in California and all over the country, and there wouldn't have been a precedent established barring the Army Corps of Engineers from coming in and doing whatever they wanted.

Breslin: Was the environmental community happy to have the support of the disability community?

Pachovas: Yes, absolutely. Yes, it was a very interesting wedding, especially since those of us who were actually out there doing it had very little actual relationship to the folks in Washington that were doing all the lobbying. We had some of the major players in the disability community and environmental community back there in Washington deciding strategy and what needed to happen next, so we were basically just the vehicle. We did very little but sit in mud for ten days, but it was important that we did.

Breslin: Well, you didn't see anybody else sitting in the mud for ten days!

Pachovas: That's true, it didn't happen. So to the extent that that was helpful, I think that a lot of people were able to use it to everybody's advantage.

Breslin: Has there been a lasting alliance between the disability community and the environmental community?

Pachovas: No, no, I'd have to say no. I mean, there's very small stuff, but not as a formal marriage. There are a lot of disabled people who are working on environmental causes, and I think that's really very good, but by and large, still, the environmental community doesn't consider access into those areas as a major priority. Subsequent to that, I've been in major arguments with groups like the Sierra Club about whether or not we should be allowed access to fire trails to be able to get into wilderness areas. So there are still fights to be fought even with those folks that ostensibly were there to safeguard our national resources.

Breslin: What impact did this have on you, personally--the action and the outcome?

Pachovas: Well, you know, it gave me some spunk, I guess, and it gave me the courage to take on the next chore, which was to organize something which ended up being the Disabled American Freedom Rally a couple of months later. It gave me some political contacts and an ability to convince people that I was capable of doing what I said I was going to do, and that was very helpful to us when we were doing that organizing.

Disabled American Freedom Rally, 1981

Breslin: So tell me about that action; that's sort of the next major thing that went on with you.

Pachovas: Yes, one of the more major things in my life was the Disabled American Freedom Rally, which was a twenty-city cross-country tour that had originally been scheduled to do more cities. We were supposed to have a northern route and a southern route, the northern route going across the plains states and the industrial cities, and the southern route going through the south and then meeting us up together in Washington. But the southern route, without our ability to go down and actually plan it with them, fell apart.

So we had scheduled a major tour of a couple of dozen of us that would go by bus, and car, and truck, and whatever we could manage to beg, borrow, and steal, to go across country, because it was the "Year of the Disabled Person." The previous year was the "Year of the Child" at the United Nations, and most of the children's programs that were really of import were dismantled during that year. So I was concerned that Reagan was coming in, it was going to be the "Year of the Disabled

Person," and what was going to come out of it was that we were going to do a bunch of dog and pony shows saying how much we were grateful for our lot in life and the administration was going to radically cut the programs that provided our lifeline support.

Breslin: This was 1981?

Pachovas: This was in 1981, just after the heels of the wilderness action thing which happened in January. So by April we were in full-tilt-boogie organizing. You know what I had no interest in doing was in starting another organization, though, and that's where this whole notion of trying to get a movement together was important, at least in my mind. I thought that if we ever tried to do this together through some organization, it was just going to fail because there were enough of us ego-maniacs all over the country that it would be very difficult to try to do something under somebody else's umbrella. Everybody felt no matter whom, it just seemed like there was this atmosphere within the organizations that their organization--

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Breslin: Finish your thought about the organization.

Pachovas: Yes, there were more damned disabled organizations during that time that didn't work with each other than there were that did. I thought that that was not a good situation. You have to remember, back in those days, I'd been doing a lot of writing and thinking about institutions and what happens to them, and one of the things I started realizing was that we had begun to start institutionalizing the movement and that it wasn't a healthy thing. So I tried to figure out, on a bunch of different levels, what might be effective.

One of the things that I wanted to base this thing on was that we were going to work together as a community; we weren't going to threaten anybody's status as an organization, but we were going to try to prompt them to do something to acknowledge this year besides just a dog and pony show. We didn't want to try to tell them what to do. But we told them that we would be coming across country and here's when we would be in your city and if you wanted to do something during that day, we could bring a few dozen people to provide some energy into whatever it was that you wanted to plan. We gave them lots of suggestions. We sent out lots of material about what was happening in California with the access laws, about what was happening with the independent living centers out here, about what was happening in transportation, so we just kept feeding

people in places who said they wanted to do some organizing information about what was going on here in California.

Now in 1980, you have to realize that--and it's still probably true today--that California was pretty much what was happening in disability civil rights movement. There are a lot of folks here with a lot of energy going off in lots of different directions and the product was good. We wanted to pass that on.

Common Ground Issues

Breslin: Let me just stop you for a second and have you say a little bit about what the actual issues were that sparked the idea of this movement?

Pachovas: Okay. Well, the major issue was that I thought we needed to build some community and that this was a good year and a vehicle for doing that because it was the "Year of the Disabled Person" at the United Nations, and sooner or later people were going to start writing about that. I wanted them to write about some of our issues, rather than how noble we were, or heroic because we survived our disabilities. That was the major overall thing.

Then there were a lot of obstacles. Now, what we seized on was common ground. At that time, the Congress was proposing the Graham Lata Amendment. Graham Lata was a way of cutting back social services. Reagan was coming in and he wanted a military buildup, and he wanted to cut back social programs and social spending. So what they proposed was it would be fairest to everybody if they just cut every program, every social program, by 20 percent, regardless of how large, how small, how fat, how lean. We felt that specifically cutting rehabilitation programs would be devastating to us.

Breslin: When you say rehabilitation programs, what do you mean?

Pachovas: I'm talking about all federal money that goes into any state vocational rehabilitation program.

Breslin: So voc rehab is what you're referring to.

Pachovas: Voc rehab, yes.

Breslin: Any other disability programs that seemed likely to be subject to that cut?

Pachovas: Yes, there were lots of smaller ones, lots of stuff on different levels around health and what was going on with transportation. There were boards that were scheduled not to exist anymore. I'm not sure, now, which ones they were, just can't recall, but the most devastating impact for the average person was that their state voc-rehab would not be receiving any federal money, or would be receiving many less dollars. We felt we just couldn't take that hit in voc-rehab. Whatever was going on in other programs, we couldn't afford that hit right then, so we got people to rally around that specific issue. We would do this tour going across country where we would do a rally in cities as we went along, and then we would all meet together in Washington, whoever wanted to, and then go march on the Capitol and tell them not to do it.

Complex Strategy for Public Support

Pachovas: The strategy behind it was fairly complex. I mean, what we knew we had to do, at the time, was arouse public support, again, and awareness about what the situation was. Reagan had just come in as president and was going through this honeymoon period with the press, so that anybody who had anything negative to say about him whatsoever was just squelched. The press seemed to have an attitude that this was a royal presidency and that they wanted to give the guy a chance to hit the ground and see what he was made of, so they were pretty much not being negative about anything he had done up to that point and were sitting back to see.

Breslin: So this was basically early '82.

Pachovas: Early '81, his first year, just coming into office.

Breslin: Is that right?

Pachovas: Yes, it was. That was '81 because he was elected 1980. But I knew that we were in trouble with Reagan being president, you know, he wasn't going to help us at all. He didn't do squat for us when he was governor of California, and I didn't think he'd do any better as president.

Breslin: Were there any other issues that you were concerned with, that you were aware that Reagan was involved with, or interested in, that also became part of the calculus?

Pachovas: Well, we knew that he wasn't much of an environmentalist and that environmental programs were going to suffer with his being there, which is why we previously agreed to go and sit up in the cold Sierra foothills of January.

Breslin: In the mud.

Pachovas: Yes, because we were just hoping that Carter would make the decision before he left office. We didn't think that Reagan would do anything for us. As a matter of fact, I told the press at the time, "Look, I don't think Reagan gives a damn about any of our rivers." Of course I kept getting admonished by our press people saying, "Quit saying such anti-Reagan things. He's the darling of the press right now, and you're saying terrible things about him." Now, in retrospect, I'm really happy I did say terrible things about him because I feel like there was a certain sort of prophetic air to that.

Breslin: So this organizing occurred primarily in the Bay Area?

Pachovas: Yes. No. Actually, no, it happened all over the country. All over the country there was organizing being done. The first thing I did was call every person that I knew that was in a leadership position anywhere around the country that was in our route. First we had to plan the route. The route that we chose was very carefully chosen and the timing was. We wanted to catch the Congress and the Senate home--when they were back home in their districts and had to talk to their people at home--which meant to us after the July break and before they readjusted after Labor Day. We wanted to get, especially, heat brought on those congresspeople and senators that were on the finance committees, so we specifically targeted the cities and areas where the finance folks were that were in the Congress. We wanted to pick cities where there was strong labor support and strong church support for what we were trying to do because that was the ability that we were going to have to go back and forth. I mean we left knowing that we didn't have enough money to get there and back, but that we would probably do okay.

So we sent word to everybody who was along our parade route, saying we're going to make it to this place, we'll be there on this date, plan something, do something. You know, if you want to go do demonstration, we will be there and add numbers to your demonstration. If you want to go talk to your

local congresspeople and your local officials about access stuff, we'll provide you information about what we're doing out here and show up and help and talk about that. If you want to do whatever kind of media thing--or even a picnic--we don't care, just do something.

Breslin: How did you contact people in various communities? What was the basis for the network?

Pachovas: It spread. First we got lists. We got lists. Well, back then I used to go to the president's committee [President's Committee on Employment of the Handicapped, now called President's Committee on Employment of People With Disabilities] meetings every year, so that was a good beginning point. Mary Jane Owen back on the president's committee was incredibly helpful to us. She provided us with lots of lists of movers and shakers that would continually come to the president's committee meetings, and so that was the beginning of our list of who to contact. We started making personal phone calls, and as it grew, we kept posting people--wait until this plane passes--[loud plane noise and inaudible comments] Live from the Oakland runway.

Breslin: [laughter] Carry on.

Pachovas: We kept people informed constantly on our progress. We had a bi-weekly newsletter that went out, talking about who was supporting us, who was doing what in what area. And the numbers grew. As more and more of the disabled leadership saw the names that they recognized, the more credible the whole notion seemed to be to them, so it kind of grew that way. They said, "Ah, well, if Pete's doing it, or Mary's doing it, or Greg's doing it, I can do that. Yeah, we'll all do it, you know, what the heck."

We kept pushing over and over and over again that we're not going to be an organization. We just wanted to go do a community event and that your organization can host it, we don't care what the name is, what you do, what your affiliation is, whatever. That was more difficult in some cities than others. For example, Boston was a nightmare. They had five independent living centers, none of whom crossed any of their neighborhood lines. They all hated each other so there was just this warfare going on with the Boston independent living centers about who spoke for Boston's disabled population. There was that kind of divisiveness everywhere. So rather than try to figure out who to contact, we'd contact everyone and say, "Hey, we're showing up in your town, you want to do

something? Let's go do it together," and then we'd move on. So the biggest struggle for us was that.

Caravan and Support Network

Pachovas: What we didn't really count on was that our vehicles didn't hold up. You know, we thought our biggest problem would be our bodies holding up, and it turned out not to be the biggest problem. It took us three and a half weeks to go across country. We chose to pick the three largest media centers along the route for a weekend stayover because we knew that we couldn't go 300 miles a day and then hold big events every day and not take a break.

Breslin: What centers were those?

Pachovas: Salt Lake City, Denver, and Chicago, and then we stopped briefly in Pittsburgh right before we went into Washington.

Breslin: Back up a little bit and tell me how many people left the Bay Area on this caravan?

Pachovas: I think twenty-six. Twenty-six of us left. Along the way people came and people left according to their work schedules, so we would have people fly in a lot of these places and meet us in towns and pick up with us. Then other people had to go back to work and would drop out and so it was always a fluctuating kind of crowd. And it was an interesting band. Then some people would go with us to the next city or to the next major stopping point, and it was kind of fun in that way because people would come from all over the place to meet us, especially during the weekends, and we would be in one place together. We had wonderful events, but we ate way too much chicken and spaghetti. [laughter]

One of the more fun things about it was that we got very good about sharing the leadership. Everyday we appointed somebody new to be the officer of the day and they had the final word on whatever was going to happen, and we just rotated it every day.

Breslin: And how did that work?

Pachovas: It worked fine. It was very fun, yes. I think everybody loved being king for a day, and so that was good. We decided that because one day one of the vehicles broke down and we had five

mechanics standing around this damned vehicle trying to fix the carburetor and arguing about how it was supposed to be done. We decided, you know what, somebody's got to make a call here. I didn't want to have to do it. I wanted my job to be making sure that we had all the press materials together and that we were staying somewhat coordinated with what was going on in Washington.

We had a person in Washington then. That was Gary Brickman. We had somebody back home working the Berkeley end of it, and we wanted to make sure there was some coordination so by the time we hit Washington we'd know we were going to do something. We knew also that we weren't going to get national press as we went across country. It wasn't going to happen.

Breslin: Why did you think that you weren't going to get press?

Pachovas: Because of this whole enchantment with Reagan. We were saying very anti-Reagan things and very anti-Congress things; we were telling them that we couldn't afford these cuts and telling people what the impact of these cuts would be. We had projections, we did our homework on it.

As we went along, we all had CB radios and we would talk to truckers along the way who were wondering what the heck this is all about because they would see all these cars that had brightly painted Disabled American Freedom Rally stars and stripes, and all this stuff on with wheelchair symbols, and didn't know what to make of it. It was really good we got the CBs because a lot of time we would be kind of lost from each other. Well, along the route, the FBI got very freaked out about what we were doing.

When we left, we'd picked up an interpreter that none of us knew, a guy named Chuck from San Diego.

Breslin: Remember his last name?

Pachovas: Not at the moment. I did, but I can't remember it. But he was an interpreter, and we had some of the old time Berkeley activists who were able-bodied going with us, like Bob Sparks. He was great having along on the Freedom Rally because he loved conspiracies and could sniff one out even when there wasn't one. So Bob was convinced that Chuck was a federal agent and was here to spy on us. My attitude was, we don't have anything to hide. None of what we're saying, you know, I wouldn't tell the president.

Breslin: That would have been an infringement on your citizenship rights.

Pachovas: Yes, what is the problem here? They would say, "Aren't you afraid the president's going to do this and that?" And I said, "No, we'll be glad to talk to the president about what complaints we have about what a hard road to hoe, you know, this is for us, and what a struggle we're having in America not having civil rights." So as far as that was concerned, the major rule was no dope. You know, nobody could have any dope on the freedom rally--no marijuana, no anything. No booze when we were traveling, because I thought that that would discredit us instantly, if we got arrested for some stupid pot bust.

So off we trucked. We just kept going along. As I said, the thing that would mainly happen is that our vehicles wouldn't hold up to us, so we'd have to leave vehicles, literally leave vehicles by the side of the road and try to get other people to bring vehicles out to us so we could keep on trucking.

We had a couple of wonderful women--Michelle Martin and Shitara, who was married to Bob Sparks at the time--who were our resource people. What they would do is go get us whatever we needed. If we needed wheel bearings, they would go get us somebody who would volunteer wheel bearings. If we needed a car, they'd go find a car for us. You know, whatever town we hit, they knew we were coming ahead of time. We would talk to all of the truckers as we were going down the road with our brightly painted trucks and tell them what was going on, so there was this constant exchange of information going on along the superhighways of the country about what we were doing and why it was so hard and what the issues were.

So there was this kind of interesting network of truckers that went back and forth along the major highways. They would also make sure that if we had needs, they would show up at the next place that we were going to. So through their own network there was an interesting set of things that was happening. We would call back to the office, too, and tell them if we needed resources, you know, to send them to the next city or to let people there know we needed them.

Breslin: Why do you think this issue was compelling to people who weren't involved with it, like truckers and whoever?

Pachovas: Beats the hell out of me, but they sure loved it. They just loved it. I think they just felt we were kind of ballsy and we had some nerve getting into Reagan's face, and they loved it.

I think that everybody--you know, you talk about these independent truckers, I mean, they're as red, white, and blue as anybody I know, but--they're not party line people by a long shot. Independent wildcatters have a mind of their own, so I think that struck their fancy that we were independent, too. We weren't just buying whatever it was that the federal government fed us and that we could see a bad thing when it was coming. So I think there was respect for that.

I think there was sympathy because we had severe disabilities. When they would see us, they were just dumbstruck that such a group could arrive anywhere. We were very severely disabled folks that would show up. We had five attendants and like twenty disabled people that needed attendant work. We would go to a place, we would have to drive 300 miles a day, and then arrive at a city and then partake of whatever they were going to do. By the time we got to bed, it was two, three in the morning. We'd have to get up at six and start all over again--getting dressed and being on the road by nine or ten o'clock so we could make the next 300 miles, so it was very grueling.

We slept on baseball diamonds, we slept in church basements, we slept in orthopedically handicapped children's schools, we slept at a military installation in Ohio, in an army barracks. We slept in the dormitories at the University of Michigan with the jocks, and that was an interesting shower room scene, I'll tell you: us and the football players. Talk about a contrast in style. [laughter]

Breslin: Were there women on this trip?

Pachovas: There were men and women, and I'll tell you it was a pretty unisex kind of thing by the time we'd gotten to Washington.

Fear in Washington and FBI Infiltrator

Pachovas: The federal government got increasingly panicky about what we were doing. It was kind of interesting, they were more on top of what we were doing than the national press was at the time. But they sure were on top of it.

Breslin: How were they on top of it? I mean, what's an example of that?

Pachovas: Well, one example is that Bob kept this narration going on, because he kept a very close eye on Chuck. Every time we would

go to a rest stop a car would appear with men with dark glasses and Chuck would go back and talk to them. So it didn't take a brain surgeon to figure out there might be something going on with this. Chuck was gay, so I don't know if this was just kind of a pickup thing going on, or whether there was some credence to what was happening in Bob's brain about it being a big conspiracy. Especially in the beginning we weren't sure. So we kept feeding information to Mary Jane Owen about what we were doing and where we were--and she was on the president's committee at that time--and it turned out that the FBI was getting their information about us from the president's committee.

Breslin: And the president's committee is the Presidents' Committee on--

Pachovas: On Employment of the Handicapped.

Breslin: Okay, that was then called employment of the handicapped.

Pachovas: Yes. So Mary Jane Owen, who just loved us and was an old Berkeley person herself, would get what we were saying and then tell the FBI that this was the truth. Then the FBI would make reports based on what she was saying, which was what we were telling her to tell them, and every once in a while we'd get these wonderful reports from the FBI on our activities. We would read them at dinner. They were just wonderful because they were saying all kinds of good things that we wanted them to get. When we'd gotten to Michigan, the paranoia by the federal government was so great that there was a radio patrol car over every overpass along the superhighway as we went through. A radio car just stopped, watching our caravan go through.

Breslin: What do you think the FBI was concerned about? I mean, given that you were--

Pachovas: Jeez, that's a good question.

Breslin: Since you were being completely forthright about your agenda, and you weren't breaking laws, you were exercising your right to free speech and organized and so on, what was the issue?

Pachovas: To me, at that time, I was surprised that they'd take any interest at all. To what extent it might have been seen as a threat to the president, I don't know, a legitimate threat to the president, I don't know. Could we be a bunch of radicals? I mean, they knew what my history was. I'd just done the Stanislaus Wilderness thing and hassled the hell out of one president and here I was on this thing going to another.

I tried to keep kind of a low profile as far as my being the organizer-type person in this, because as I said, we had a different person in charge every day. I think that the president really wanted us to stop doing what we were doing because we were upsetting the applecart. We were just destroying his plan. We would go to a town and drag that damned congressman and/or a senator to that function.

Breslin: It was bipartisan representation in those places?

Pachovas: Absolutely. Absolutely. Yes, there were no lines on our caravan, even though it was microcosm of what was going on in the disability community. We had deaf people, we had blind, we had people working with us, you know, who were vets, who were not vets, who had many different colors, who were severely disabled, who were not as severely disabled, who had hidden disabilities--it was this great kind of melting pot. It was very difficult for them to put a label on it. They really wanted to be able to put a label on it because then they could discredit it in whatever way that label would present itself.

I didn't realize how successful we were at it until I read the final summary giant report about the time we hit Pittsburgh. It was a great report on our activities from the FBI. I think it was written prior to our leaving San Francisco, about what we were all about. It said basically that here was a group of people that seemed to lack any kind of central organization, that was made up of a lot of different kinds of people with different backgrounds. It mentioned me and Jane by name because we had been notorious before. Jane Jackson, right. They said that it seemed to lack central leadership and funding. There were veterans and non-veterans and people of different kinds of disabilities and different ethnic minorities and they couldn't quite get a handle on what it was as a whole group, but that we were determined to go.

They could foresee one of two scenarios happening: we would either leave San Francisco and be successful and it would be very embarrassing to the administration, or that we would fail to get there, in which case we were probably savvy enough to turn it into a metaphor for what a tough row to hoe disabled people have in America.

Breslin: That's fairly smart from the FBI.

Pachovas: It was, it was, and I think it was because Mary Jane fed them this. At the end of it they said, "Well, it's raggety, but it's real." [laughter]

Breslin: You mentioned Jane Jackson. What was her role?

Pachovas: Jane initially was very helpful. Jane Jackson is a disabled activist living in Oakland who does a lot of different things now and has a lot of church contacts. She's been primarily, now, working with people in Cuba and the disabled population in Cuba. But she's done so many different things and so many projects. She's just an activist at heart and in life, on whatever cause comes by. But she had great church contacts, and so we were able to organize through the Riverside Church in New York and through some of the other networks that she had, being able to get us church connections to support in the towns that we would be going through. It was invaluable to us. She did go partway with us. She met us in one of the towns and then went the rest of the way with us.

Demonstration in Washington

Breslin: So what happened when you got to Washington?

Pachovas: We were very tired and it was a zoo. It was a zoo. In Washington we were staying in a school building, and a lot of people had come in from a lot of different places to meet us. There were a couple thousand of us there. We had scheduled to meet in Lafayette Park, right across the street from the White House. The press kept saying, "Do you want a meeting with the president." We kept saying, "We don't really care whether the president wants to meet with us or not, the point is we want to talk to the American people about what we're doing."

Well, during the week that we were there, the president had singled out this young woman who had gone across country in her power wheelchair behind a giant Winnebago life support system, so that at night she was back in the Winnebago: it was very plushly appointed, she'd sleep in a nice warm bed, eat real meals, do all that kind of stuff, and then they'd change the batteries and then the next day she'd go as far as she could by batteries and then when she couldn't go any farther, she'd go back to the Winnebago. So the president invited her to the White House.

Breslin: Do you remember her name?

Pachovas: No. Tried to do this whole, huge choreography around her being there. In the meantime, there are a couple thousand of us raggety people out there in front of the place who he was

desperately trying to ignore. We kept saying, "We don't really care if we meet with the president," which was this odd thing for them, because this wasn't a big deal to us about that. We were mostly interested in what Congress was going to do, so we decided that we would have a big rally.

Breslin: You had a Democratic Congress.

Pachovas: We had a Democratic Congress at the time, but we had very good bipartisan support, especially because Lowell Weicker from Connecticut, a Republican, and I think Austin Murphy might have been a Republican from Texas, anyway, we had good bipartisan support for what we were trying to do and for the disability stuff. Although they were all liberals. I mean that's the difference between what was going on in 1980 and what's going on in 1998, is there were liberal Republicans. You don't see that much any more. There were even liberal Democrats then.

Breslin: So were they persuaded by this problem then? Well, did you meet with members--

Pachovas: We did. We had a series of meetings with different people there, but mostly we marched on the capitol and it was a zoo. It was a zoo. Wavy Gravy flew out--

Breslin: [laughs] And who's Wavy Gravy?

Pachovas: Wavy Gravy was the M.C. for Woodstock, and he's a Berkeley person. His real name is Hugh Romney, and he wears a clown suit and they even named an ice cream--Ben and Jerry's Wavy Gravy ice cream--is named after Wavy Gravy. And Wavy Gravy had a foundation called the Seva Foundation. He's the head of it, or, I don't know exactly what his relationship is to it other than he was the founding spirit behind it. Seva Foundation flies doctors into Southeast Asia to give vitamin D shots to people so they can eliminate nutritionally caused blindness. So he has his rock star friends hold benefit concerts all around the country at different places to raise money for Seva and also for his Camp Winnarainbow here in California where he teaches children how to be jugglers and how to have a good time.

He was our grand marshall and came with his clown suit and red nose and did all that stuff. We went and marched on the Capitol. What we decided was that each of us, from wherever we were from, were going to talk to our congresspeople when we got there, so we did a massive lobbying once we got there. Congress voted to withdraw rehabilitation programs from the Graham Lata Amendment. It was the first time that Congress had

not given the president what he wanted, so the president wasn't too pleased with our being there.

Stoned on Hash Cookies

Pachovas: We had this last speech that I'd been trying to prepare for. Mostly along the way, I'd been doing pretty extemporaneous talks, but I really did want to prepare something to say when we'd gotten to Washington. I wasn't sure what it was going to be, but I did want to prepare something, so I started working on it when I was in Michigan. Through Ohio and Pennsylvania I started trying to get something down on paper.

Well, the day that we had the big to-do and the big picnic in which we invited whoever wanted to show up, Gary Brickman had lined up a whole series of speakers, Ron Dellums, got Ted Kennedy, all the liberals in Congress, who also just seized the opportunity and wanted to speak about how cool we were. I was supposed to be the last speaker to kind of focus in on why we were here and what we were about to do next. It was supposed to last an hour, which went on to like four hours of people coming and going and coming and going. Every time some other famous politician would come up, Gary Brickman, who was just star struck, would say, "No, wait, wait, wait, we've got to put them on."

What was happening in the background is I was having lunch and Wavy Gravy said, "Here, Boss, eat these cookies."

Breslin: Oh, no!

Pachovas: Well, so I ate these cookies, which were just full of--

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Breslin: You were saying about Wavy Gravy and the cookies--

Pachovas: Well, we had all brought lunch and we were feeding people and we were sharing food, and all that went around. At one point Wavy Gravy said, "Here Boss, eat these cookies," and he gave me these five cookies that were laced with hash. I had no idea they had anything in them at all because they just tasted like cookies to me. So I was chewing on the cookies and trying to prepare my speech and getting ready. Jeez, about two hours into lunch I started feeling kind of light-headed and kind of

good. I thought, well, at least I'm relaxed a little bit; finally I think the tension has just left. Well, that kind of exacerbated as the afternoon grew on and I started realizing I was stoned. I was looking at my paper and the words were not staying put, and then I realized, "Oh, no, this is not good."

I started trying to signal over to Brickman to cut these guys short and get me on there when I was still coherent because I realized at that point that these cookies had something in them and it was only getting more intense as time went on. About the third hour, I kept trying to signal over to Brickman to cut it, let me get on and get off of this thing before I lose my ability to speak. But Gary Brickman was way too star struck. Oh, no, Kennedy would show up, Dellums would show, oh, no, we've got to get them on. Weicker would show up, they've all got to talk about us. I'm getting more stoned by the moment.

And about the time I looked at my sheet of paper and words started moving around, Brickman introduced me.

Breslin: Oh, dear.

Pachovas: I knew I couldn't read a God-damned thing I'd written. So I thought, you know, I've got to say something, so I thought I'd just go up and I'd wing it. So I got up and I started speaking. I haven't a clue, I haven't a clue about what I said that day. I'm just blank as far as my memory about what it was I said that day. But I do know it must have been good, because one of my guidelines for if I was on target was to find Michelle, who was my lover at the time and who was out in the crowd, and to see if she was crying because if she was crying, then I was saying something that had some sort of emotional impact. So I'd be talking and I'd look out into the crowd and see Michelle and as long as she was crying, I kept talking.

Breslin: Oh, God. [laughs]

Pachovas: I thought, okay, something's hitting home, you know. I said something and I got off and I don't know how long I spoke and I don't know what I talked about. People kept saying, "Oh, that was the most moving speech I ever heard. That was so brilliant." I don't remember a word of it. I have no idea what I told those people that day. I could of told them we should all go trout fishing for all I know.

Breslin: No one recorded it?

Pachovas: You know, I think people did record it, but I never bothered finding out.

Breslin: You've never listened to it.

Pachovas: No, I never did. Shortly after that we went and marched on the capitol, which I was grateful for because I needed the exercise at that moment and to clear my head a little bit. Then we had to work on figuring out how to get home.

Breslin: Get back. So what was the impact of this very long and arduous effort? You set out to reach certain goals. Do you think you reached them?

Impact of Freedom Rally

Pachovas: Well, we reached the goal of being able to pull rehab programs out of the mix. So that was our short-term goal. I've gotten letters from independent living programs and from disabled activists for more than ten years after that that were similar in theme to, "We're really glad that you stopped through our town and now look what we've done." They would send me press clippings or legislation that they had passed that brought about accessible public transportation, or independent living programs. That was another thing that we had recruited for. We wanted to stop in cities that had budding independent living programs or people who wanted to start them in their towns. So for lots of years I would get an occasional letter from someone saying, "Thanks, we're really glad you did this. Let's do it again."

There was a huge push the next year to do it all over again from a lot of different sources and especially to form a political organization, and I just resisted that with all of my might. Number one, I had no desire to do all that work again, and number two, I just thought it would be the death of what we'd been trying to do, which was to form some sort of community event. I had hoped that that would involve as many different people as we could, given the resources that we had and doing something that we felt good about.

So there were a lot of diverse folks who ended up being in Washington. I don't know if they would have showed up there anyway or not, but it was an interesting group. We were pretty focused on lots of the notions that we've been talking about, so it was good in the smaller groups. You know, we didn't

really plan workshops and all this. We had a couple of workshops on what we wanted to talk to Congress about, but short of that we didn't really hold workshops on all these different things that we'd been doing in California. We did pass information on to anybody that wanted it. So we just kept that stuff flowing. Then we packed up our marbles and went back.

I think that on the local level, in a lot of places it was very helpful because it helped bring public attention to what they were trying to do in their community with independent living. I think that the collection of all that was helpful to us because we passed. We got Congress to pass the Graham Lata Amendment without rehab being part of the mix. I think that it helped people connect even more who were working on specific things and get to know a wider network, because we freely gave information out about who was doing what where.

We were a good resource contact for that kind of information for a lot of years. People would call us and say, "Do you know who's working in this city or that town?" We'd share our lists. I think that the most important thing on an organizing level or an institution level that we did, other than not becoming one, was to pass information. I think that one of the ways that organizations tend to control the movement is through the dissemination or the lack of disseminating information. If you're the only one in town who knows what's going on and tell people at the last minute that there's a crisis, oftentimes they're going to follow you blindly because they believe that there is a crisis, versus questioning whether or not you should be leading whatever it is that's happening with regard to it. So information flow and control is one of the keys to keeping the movement alive. It's a problem because we don't really have a good mechanism. Now that the internet is up and running, I think that that's a better mechanism than anything I've seen so far for that kind of organizing along issues.

Breslin: It's an uncensored flow of information.

Pachovas: Yes. Yes, and an uncontrolled flow, too.

Breslin: Yes, that's right. Well, that's quite a story and quite an achievement. What was next for you when you got back?

Pachovas: I think then I was working on helping free Sharon Kowalsky. No, actually, right after that the toll that it took was that Bronson West, Bob Sparks, and I all lost our relationships somewhere on the road. Our relationships suffered so badly.

They just all went to hell, and so the toll on all of us was enormous. What we decided to do about it was that the three of us went down to Diablo Canyon and joined the Livermore activists down there who were going down to protest the nuclear site down there at San Luis Obispo. So we went directly from here to there.

They all knew what we'd been doing. I don't know how the word got out. I remember being there, I mean, just so tired. We just like laid down on the ground. Wavy Gravy, of course, showed up for that, too, because that's kind of what Wavy does --he does go to those big events--and introduced those of us. All I could do is like manage to wave my hand from the ground, just lying in my back. Just gave my arm, and like, hello. So they were all excited about our being there after what we had done.

I think that, too, was a good experience for the other movements. More and more we are taking place in what happens in other venues besides just disability rights.

Disability and Broader Issues

Breslin: Do you think that there was any perception that there were disability issues in these other broader issues, or do you think you were perceived as activists with disabilities who support anti-nuke or anti-flooding the river projects?

Pachovas: I think that they would have preferred to think of us just as the latter because most of them were so damned inaccessible and had so little consciousness about what it took them to make themselves accessible.

Breslin: You mean, personally inaccessible?

Pachovas: Yes, they would hold meetings in places that were not accessible.

Breslin: They were personally inaccessible?

Pachovas: Yes, they were. They would hold meetings in rooms that were inaccessible and buildings that were inaccessible and be embarrassed about it--didn't want me bringing it up for sure--and because of this PC kind of stuff.

Breslin: Did you bring it up?

Pachovas: Sure.

Breslin: Were they eventually persuaded?

Pachovas: Some were, some wanted to ignore it and think they had a greater issue here with what they were trying to achieve. So you learn a little bit to grin and bear it, but try to just keep pushing the envelope. Little by little it soaks in. It soaks in. People start, if not immediately attending to it, are more mindful of it when they go other places.

Breslin: Was there any institutional or organizational support for what you were trying to do in these couple of three years from, you know, the organization in Berkeley that--

Pachovas: Very little. No, very little. As a matter of fact, I think that they felt that this was a threatening thing to their relative positions in the community. But it was a position that I was kind of used to at that point, as being kind of the bad boy, you know--in the neighborhood--just having in my own mind, which was not a good thing, I guess. But no, they weren't helpful to us.

Breslin: Were you involved in any of the issues the organizations were involved in?

Pachovas: Well, I would think that most of the folks would be involved in what was going on with voc-rehab, especially the independent living programs, transportation. Yes, sure. Yes, we're talking about lots of different issues: transportation, access, specifically the Graham Lata stuff, involving diminished support for voc-rehab. But we were talking about what it was like to be disabled in America all around the country.

Breslin: So, what was your thought about what was next for you when these series of events wound down?

Pachovas: To be honest, you know, making sure that I had a job, getting back to life, being normal. It's a strange thing. You know, I've thought about it since we last met, about why do I even do this stuff, and I can't give you a good answer. You know, I don't know. I think that I do it because it makes me feel better about myself and not such a burden and I think that's the main reason. I know that God gave me some kind of skills and talents and it'd be a shame to just waste it. That I lived when I broke my neck and there must have been some reason for it. But other than that, that's kind of it.

One of the notions that bugs me is that so few people actually do something about our sorry lot in life and depend on other people to do it. They'll say, "Oh, well, Mary Lou likes to do that kind of stuff, or Judy likes to do that stuff, or Michael likes to do it, so we'll let them do it." Hell, I've got to tell you, I don't like doing this stuff. I think there was a time that I did like it, but that hasn't been for at least twenty years.

Breslin: That long?

Pachovas: Yes, I think that long, yes. Now I do it sometimes just because I'm pissed off and I'm not a good victim, and sometimes because I see a need and I think I can make the place better, and that makes me feel good about myself.

Impact of the Disability Rights Movement and the Momentum from Berkeley

Breslin: I have a couple of questions that have not to do with a linear evolution of your time in Berkeley but more about your observations about both the impact of the movement overall, including your personal contributions, but also the impact of the moment as you look around you, and not just locally, but around the country. Also, a question about leadership. I want you to reflect a little bit on what you think the impact of the movement has been, or do you think it's had an impact?

Pachovas: I think we've had a tremendous impact on our society in general. I think that more and more places are acceptable of people who have disabilities and accessible to them physically. I think that twenty-five years ago, we were about 500 years removed from civilization and now we're only about 100 years, so I think we've made good gains in twenty-five years and if we can keep that pace going, that will be really good.

Breslin: Do you think that the movement that developed from the Berkeley community has played a significant role or not?

Pachovas: Absolutely. Without a doubt. I think that the work and the inspiration that people specifically from Berkeley has carried into the community has changed our society. I don't know how else to put it. I just think that we made a fundamental change in the way that society, not just ours, views people that have disabilities.

It was incredibly important that Ed got the University of California to let us go to school there, that people before him got people to give them guide dogs. You know, those things were so important! We can talk bad about this person or that person, or this thing or that thing, but there's no denying that all of us together have created major change in a way that I would say is unparalleled in any other social movement that I've known about, because it affects so many different institutions. It isn't just something where, okay, well, we'll allow you to come into a place where we wouldn't allow you to before. Now, you've got to spend money to include us into those places. I mean, we are a group that costs people money, and that's not an easy sell. If you can sell disability to civil rights, you can sell anything. [laughter] Because it's expensive. I mean, we've got to convince people that they should be spending money for maybe not, you know, a personal reason. That's very difficult to do. So I think that that has had repercussions.

At some point I think on a more individual level that it encouraged a number of people to take part in other things that are interesting to them when they might not feel that there is a place for them in the disability civil rights movement. I think that we've given them, number one, the freedom from fear of having to stay home, because otherwise something bad might happen to them, and that you can go ahead and have some chutzpah and go out there and make a change, despite whether or not you have a severe or not disability. And that courage, in that sense of taking those steps away from a life of dependency, opens a lot of doors. It opens a lot of mental doors in your own mind and it opens a lot of physical doors in other places.

I think that other movements are more willing to accept those of us, maybe initially because we represent a constituency, but they let us in that door, into whatever it is they're working on. Once we get in the door it's pretty much up to us to either keep that door open and run with it, or to know that it's going to shut behind us again. So there is a responsibility in some way whether we're willing to accept it or not, that society is going to look at us in the framework of what they're doing and what their interests are.

When I go to a meeting that has to do with historic preservation, hell, hardly any place is physically accessible. Talking about a group that would normally be most antithetical to making physical changes to structures, that would be one. But when I go to a group, for an example like that, and start working on the issues that are important to them, and I'm not

stupid, and you know, actually help them strategize and figure out how to make change, then that's a good thing for all of us. I think that there's still this public perception that because we have a disability that we are not going to function at 100 percent: mentally, intellectually, or politically.

You know, it's hard for me, living in Berkeley, to have a different experience than the one that I'm having because, you know, you know your own reality. My reality is that I can go into most groups and have some credibility with them. But you have to maintain that credibility by doing good work. I have a lot of interests that don't have anything to do with disability. But the things I've learned, through having acquired a disability and struggled with that and still struggle with, have made me more able to work on other interests in a way that I don't think I would have been able to had this just been twenty-five years ago. I just don't think I would have been accepted to the level that I am now. I don't think that it's just me; I think it's all of us.

Breslin: And if you hadn't acquired a disability?

Pachovas: No, I think that if the public hadn't had the experience of having us be here, they still would not have held our opinions in much esteem or held us in much esteem.

Breslin: Why do you think Berkeley was the place where not all but a significant part of the momentum was gathered to launch this effort? What's the special deal with Berkeley, and what's the thing that makes it different from other places? Or is there anything that makes it different? Was it just purely circumstance?

Pachovas: No, it wasn't circumstance. It was a lot of hard work by a lot of people, especially initially.

Breslin: Well, why Berkeley? Why not Austin, why not Boston, why not Chicago?

Pachovas: Why, something has to start somewhere. Okay? I mean, somebody's got to be somewhere, right?

Breslin: [tape interruption] That's heavy. [laughs]

Pachovas: Actually, that's a little of the old Myron Cohen joke. [laughter] The old Myron Cohen joke where the guy walks in on his wife and opens the closet door and there's a naked man standing in the closet and he said, "What are you doing here?" and the guy says, "Everybody's got to be someplace."

Breslin: Okay. [laughs] Starting from that premise.

Pachovas: Actually, starting from that premise, look, we had Zona, who was very supportive of Ed, who came to school here. I think Zona is probably one of the most unsung heroes of our movement because I think that she had the kind of nurturing and the ability to inspire her children and the rest of us, when she was working at the Disabled Students' Program, to go and do those things, to take the steps. I think that Ed was very instrumental in opening that first door that a bunch of us flowed through. John Hessler, Don Lorence, and I could go on and on and on and on and on, and name lots of names of people that did those things.

Breslin: Why those people here, rather than some other quad in some other city at the same time?

Pachovas: A number of different reasons. Number one, the University of California, at least then, was one of the most prestigious educational institutions in the world. It had a reputation for being radical. It had a reputation for being liberal.

We have a wonderful physical climate in Berkeley. It just lends itself to disability very well. It doesn't get too hot, it doesn't get too cold, most of us can function in this thing pretty well. It's an ideal place to live.

We have a fairly easy access to entertainment, to doing those things that you can't do if you're living in a rural place, or you can't do if you're living in a big city where they don't have any curb cuts. We started laying out that foundation early in the game. We needed to make the place accessible.

I think that Ed's ability, specifically, to be our P.T. Barnum and to sell this thing to everybody nationally brought attention to Berkeley.

That the Disabled Students' Program had a very influential role in making a decision early that they were going to recruit for activists. They did. It was a deliberate move on their part to try to get activists to come to Berkeley. Because I remember a lot of times when we'd sit around calling people and we'd say, "Hey, we need to get this person over to Berkeley," and that would happen. Then when CIL started up, it was still the same thing. We would talk about, "Gee, this person lives in New York or this person lives down there and they're activists." We would say, "Well, why don't we get them over here and working on this stuff." That's how Judy got here.

Breslin: And that's how I got here.

Pachovas: Yes! You know, we were recruiting for that stuff. And then it stopped. It stopped, but luckily at the point that that stopped at the university, we had enough momentum built up that it continues to be the place to be.

Breslin: Well, that's a very interesting observation, I think. I think that's a unique observation, actually.

Pachovas: Now, like it or not, this is still probably the most accessible place for people who have severe physical disabilities. I don't know somewhere that has better amenities, better conditions for living, better support services than we do here in the community for as bad as everyone here in the community.

Breslin: For as much as everyone--

Pachovas: Complains.

Remaining Challenges: A Declining Economy and Developing New Leadership

Breslin: Extraordinarily unhappy with what's here. Which sort of raises the next question. What are the issues that you think are the most critical ones that still remain? You know, what are we facing now that you think are really serious challenges for us?

Pachovas: I think we're going to face a declining economy. I think that during this time of great prosperity in the last nine years of this bull market where everybody was making money, we've sat on our hands while the federal government has systematically dismantled social programs. It's going to get worse and it's going to get easier for them to say we can't afford it. We should have been more alert. We should have been more at the watch and we haven't been; we've been complacent. Many of us who are older are satisfied with what we've done and are happily living our own lives and want something for us now. We don't want to have to suffer every damned day. We don't want to have to be in meetings where you just wrangle and you get your stomach upset and you feel like assholes trying to convince them to do things every day of your life.

But what we haven't done is to pass the damned baton on to the next person. We haven't been good as a movement for doing that. We've got to teach younger people not only to do what we

can do, but to sit back and then watch them take over our roles and not beat them to death because they do things differently than we do. They're going to make their own decisions, that maybe different ones than we would make in that situation, and we don't encourage that enough.

Breslin: You know, one of the great paradoxes is that the movement's goal is to integrate people with disabilities and give options and choices, as everyone theoretically has choices within a certain economic context. When people make choices not to work within the movement but rather to teach or work as a banker or become a lawyer that is in private practice in a law firm or whatever, that's ultimately what we want people to be able to decide to do; so it's hard to, also at the same time, send a message to the people, "You should be taking on movement leadership roles." How do you reconcile those two goals?

Pachovas: There are a number of thoughts I have about that. One is that there are so many young people that come into Berkeley that thank God for the programs or that just reasonable-minded, spirited people decided that that should happen. I didn't sit in jail with any of those people. They're going to go off and get their MBA and go off and be happy little rich guys, not worrying a damn thing about how they got to be there, or appreciate how they got in here to get the education that they needed to get there, or feel that they have any responsibility to keep going with it. I mean, I think that the younger folks in our generation have figured out if they can make enough money, they can shield themselves economically from the problems that we face, and it won't affect them. I think it's a real selfish perspective.

What we haven't passed on is a sense of responsibility toward keeping the whole movement alive and educating them about why it's important for them to take some role in it. No, they don't have to take a leadership position, but damn, every day of their lives they're going to run into discrimination and they can make a decision on one of those occasions to do something about it. That's not too much to ask. But don't ignore it when you're being discriminated against. Do something about it.

Breslin: So in terms of the big issues, future leadership is a big issue for you?

Pachovas: I think it's a huge issue for us.

Breslin: And what strategies do you suggest?

Pachovas: It's not the only issue, but yes.

Breslin: Well, let's conclude it. What strategies do you suggest to loop people sufficiently into the movement that they can carry out the suggestion that you've made?

Pachovas: I think that one of the things that our institutions can do is hold more frequent free conferences for people to understand what their rights are. That just knowing what your rights are gives you an incredible amount of power. I think that people today don't know what their civil rights are and what they should expect of society and where they can find support.

I think we don't have enough attorneys that are willing to work for us, to resolve these civil rights grievances that we have. By far. I think that that's an area that law schools should take up more and more. Everywhere they should be teaching courses in disability civil rights and encouraging lawyers to get into this field because unless you've got the teeth behind the laws, there's no enforcement that's going to happen. So I think that has to happen.

I think that the established leadership has to learn to pass the microphone and get the hell out of the way. I don't know if that will ever happen or if it's realistic.

Breslin: [laughs] Oh, people just drop dead, you know.

Pachovas: I think it does take that.

Breslin: And are doing that.

Pachovas: Yes, it does. You know, when you start going to more funerals than you're going to weddings, you better start figuring out that you better pass this information on. We are doing that. So to the greatest extent possible, try to train new folks. Try to teach them. You can't train anybody; it's not like I'm talking about training a seal, but teach them to be empowered in their lives.

##

Breslin: Okay.

Pachovas: Whether they do what you want them to do with that empowerment is somewhat irrelevant, because I think that there's going to be enough flow over. People are going to feel like they're empowered enough to take responsibility if one of our leaders drops out. I remember when I was teaching school, and teaching

children to be wheelchair athletes, what a change that made in their lives. I just saw dramatic changes in such a short period of time. I mean, I saw children that were falling out of their chairs in their school room, and children would laugh at them all the time, get in a wheelchair--because they'd never used one before--and start to become an athlete.

Well, I'll tell you, these people never fell out of chairs again in their lives. They didn't need to. They were an athlete. It gave them inspiration, it gave them self confidence, it gave them the ability to do other things that weren't specifically related to athletics. Others that we've taught I can see down on Shattuck Avenue and they're hanging out in the street begging for change. Pay your nickel and you take your chances. Give them the tools. Give them the tools that they need, give them the education, give them a sense of responsibility, give them encouragement to be their own people in whatever way they're going to develop, but to give them support when they're doing the right thing. It's real important for us. I mean, again, I think the short term key is education.

We've got to teach our people what their rights are and we're not doing that well enough. The other thing that we need to do that's very important in our movement is to start dealing with some of the economic situations that we're going to be faced with. We're not doing that.

It still boils down to the most severely disabled people are the least represented and the least able to do things about their lot in life. There are way too many institutionalized care facilities in this country because we don't provide basic care and basic support for people who have severe disabilities. They lump us all in with the folks who are able-bodied and don't want to find a job when they talk about cutting social programs. They don't make any differentiation between people who can and can't do things. They discourage us from working in so many ways because of the threat of losing our benefits, the meager ones that we have. We can't survive on our benefits. I mean, we haven't established in our society that, yes, we're going to provide a reasonable level of care for these people. It's irrelevant, irrelevant to us, once they're this disabled, about whether they can go out and earn money, but we're going to base the ability to think of them as a disabled person by their wage-earning capacity and not by their physical limitations.

You know, if you are a quadriplegic and able to work eight hours a day, all of a sudden, you're not quadriplegic and

eligible for benefits. That is absurd. It takes away from any kind of notion of spirit or independence or willingness to try something that I can think of. It's just an absurd system that we have. We started defining disability by economic liability. So we have to stop that shit. Stop them from doing that to us.

Towards a Disabled Emergency Services Program

Breslin: Anything else on the future list that stands out for you?

Pachovas: How do you mean that? [laughs] Now I'm working on the Disabled Emergency Services Program, which I think should happen.

Breslin: Well, that's a local issue.

Pachovas: Well, starting as a local issue.

Breslin: Which is an important model for change in other places. Tell me a little about that.

Pachovas: I think that--well--

Breslin: That's your current passion.

Pachovas: Well, current might be a--

Breslin: Or commitment; not just passion.

Pachovas: Thank you. [laughs] Yes, I think that where we're at right now is that we're trying to start an emergency services program that if I had to say a one-liner about it, it would be that it would provide you with the freedom from fear, and that fear being that you're going to be in a situation that makes you vulnerable to having to be institutionalized, or vulnerable to being killed, or dying of your disability because you're stranded and you're stuck somewhere.

We've thought about this, and it was many years ago that we started trying to do this. We looked at the situation that many of us were in. Mostly we had attendants who could come to work--and then it was easier than now--but sometimes they didn't show up, or sometimes you'd need to fire them. I mean, some of our folks have been beaten. Everyone I know has been robbed by attendants. We've been beaten, we've been raped, one

of us was killed by an attendant because we have to endure this situation.

We don't have alternatives other than returning home to our parents, who are, by the way, now not alive, or having some sort of institutional care where they take care of us. Where they have one guy that's supposed to bathe and dress and feed and get thirty people up in two hours. That's our alternative right now. So too many of us, who started this independent living program you know, are having to return back, then, to their parents' homes or to institutions. Because their families were afraid for them: we can't let Michael or John or Sue or whoever live independently because what if something happens to them?

I'll tell you, older folks are dealing with that right now. What if something happens to them, what are they going to do? Whatever that might be, if something happens bad to you and you can't deal with it physically, what are you going to do? You don't call Ghostbusters; that's not going to be a big help. You've got to get somebody out there, so what we're trying to do is get somebody out to you who can help you, because we run into specific things in our community, because of our disabilities, that mainstream society doesn't.

Our wheelchairs break down and leave us stuck in the street and there's nothing we can do about it. We're not pushing home a power chair. Our attendant doesn't show up, which leaves us the possibility of calling all of our friends and burdening all of our relationships, or living close to family and burning those relationships, or sitting up in your wheelchair all night and hoping that you don't get a decubitic ulcer that turns into something worse and enduring all that pain while you're doing it.

Breslin: So when you say emergency services, you mean emergency personal assistant services.

Pachovas: We're talking about being able to get somebody who knows how to do attendant care out to a severely physically disabled person. So if your attendant doesn't show up, there's somebody who can be there in half an hour; so if you have to fire somebody right now, somebody will come over and help you; so if you have an unscheduled problem during the middle of the day--if you soil yourself and if your catheter blocks up--that somebody who knows something about it can come out. It won't be the police truck or the police car and the fire truck and the emergency ambulance--none of whom can take you off to somewhere because they don't know how to transport your wheelchair with you. So

that if you break down somewhere in the street, we can get a professional mechanic who knows how to fix a power wheelchair out to help fix you right there on the spot and keep you rolling so you don't have to miss school, you don't have to miss work, you don't have to miss your social engagements, you don't have to miss your appointments. Failing that, being able to get a van out and take you somewhere safe or somewhere they can fix you. When I say fix you, I'm talking about your whole entity.

For me, I'm a lump of clay if I don't have my power wheelchair.

Breslin: I know, we all are.

Pachovas: So we want to be able to do that.

Breslin: What's the vehicle to do that?

Pachovas: Well, right at the moment, we have an initiative, Measure E, in Berkeley's election, which will increase the parcel tax by 8/10ths of a penny per square foot, which would mean an increase of property taxes of about eight dollars a year for 1000 square foot home for everyone in Berkeley. That would provide a service that could respond within thirty minutes that would provide you with an emergency attendant, that would provide you with a van to pick you up if you're stranded somewhere, that would provide you with a professional mechanic who would fix your wheelchair on an emergency basis, that would coordinate what happens when 911 gets a call from a disabled person, so it doesn't cost \$463 every time the police car and the fire truck and ambulance show up and realize they can't do what it is that you need to do.

It would coordinate with the disaster preparedness people what happens to us when the earthquake hits, which it's going to. Right at the moment we're scheduled, according to the county plan, to be evacuated last. That's not good enough for me, so I think that we need to come up with some better planning then that.

Then to help you find attendants if you're just having a chronic problem finding attendants, to have somebody there that can help you do that, you know, better.

So those are the main things. Now, all those services are going to be free except for the attendant care part of it. That's going to cost you seven dollars an hour because that's about what the going rate is for attendants now. So it reduces

the amount of abuse--I hate that word, abuse--but the amount of abuse of the program. It doesn't make an unincentive to use it. Let me tell you, I've had to use a lot of emergency attendants this year, for the first time, because it's been so hard to find attendants in Berkeley. It is not a blessing having a stranger come into your house at some unscheduled time to work for you, and not know when you're going to go to bed, when you are going to get up, and teach somebody a routine. Every damned day, some different person. That is not a blessing, but I'll tell you, it is a blessing knowing you're going to be able to get to bed that night.

Breslin: Yes, as much control as blessing. That's the blessing.

Pachovas: That is.

Breslin: The rest of it's the mechanics that have to be made better.

Pachovas: Right.

Breslin: So this is your current major push and commitment.

Pachovas: Disability-wise, yes.

Breslin: And what's your read on the probability of it passing?

Pachovas: I hate to jinx it. I'd say it's real good.

Breslin: Well, we won't transcribe this until after the election.
[laughter]

Pachovas: Well, right at the moment, I mean, just jinx it now in my own mind. I'd hate to put the hoo-doo on it, you know. But right at the moment, the entire city council unanimously endorsed it. I have every candidate who is running for mayoral or council seats endorsing it. We're starting to pick up endorsements through the community. I'm going to all the conventions and caucuses. Other people are starting to get aboard and it's starting to spread out so that people are taking more and more responsibility to make sure that people are aware of what the tax will do. Because the first response we always get is "Oh, my God, not another tax." But as soon as we say what it does, they go, "Well, oh, yes, well, we can do that."

Breslin: Whose idea was it?

Pachovas: Oh, I don't want to talk about that.

Breslin: Whose idea was it?

Pachovas: Mine.

Breslin: What made you think of doing it this way?

Pachovas: Because we had tried to do it other ways, without much success. It seemed to be the best way to take it out of the politicians' discretionary hands. They'll have no discretion. With this pot of money, the city can't take a nickel of overhead out of it, so they're going to have to pass it on to a vendor, and that means we control what happens with that money ultimately. It's not going to be something where we're thrown into the big hopper with all the other social programs in the city, depending on what our budget looks like that year and divvied up among all the other needy groups. There's going to be a special fund of money that's going to exist forever that's just dedicated to do this function.

Breslin: Fascinating. It's a really fascinating model, which I think really kind of brings us full round to the end of our conversations, because the bottom line is that you came to Berkeley twenty-five years ago--longer than that--[and have] been an activist pretty much nonstop since then.

Pachovas: Even before that.

Breslin: And responding to the issues that are on the table at the moment.

So are there other things that you want to say or talk about or comment on or noodle on for the record before we conclude? We don't have to finish this now. We can revisit this again if things come to mind. But are there any things that come to mind right now?

Pachovas: No.

Breslin: Really?

Pachovas: Really.

Breslin: Are you sure?

Pachovas: I think so.

Breslin: All right. Well, we should leave open the option for you to revisit that question, okay?

Pachovas: Okay.

Breslin: Well, it's been a treat. Thank you.

Pachovas: Oh, I've enjoyed it, too. You've made me think about things in a way that I haven't before.

Breslin: Oh, well, it's been really interesting hearing your point of view, too. All right, Michael, thank you very much.

Pachovas: You're very welcome.

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Disability Rights and Independent Living Movement Oral History Series

BUILDERS AND SUSTAINERS OF THE INDEPENDENT LIVING MOVEMENT IN BERKELEY
VOLUME IV

Raymond Uzeta

INDEPENDENT LIVING CENTERS IN BERKELEY, SAN FRANCISCO, AND SAN DIEGO:
PERSPECTIVE ON DISABILITY IN MINORITY COMMUNITIES

An Interview Conducted by
Sharon Bonney
in 1998

TABLE OF CONTENTS--Ray Uzeta

INTERVIEW HISTORY	326
BIOGRAPHICAL INFORMATION	327
Early Involvement With Bay Area Disability Groups: The Indoor Sports Club and California Association of the Physically Handicapped	328
Volunteer and Employee of the Center for Independent Living, 1973-1976	333
504 Sit-In, 1977	336
Disability as a Civil Right and Contributions of Leaders	343
Establishment of the San Francisco Independent Living Center, 1976	345
Comments on Life as a Minority Person with a Disability	347
College Studies and Attitude Changes	349
Move to San Diego: Community Service Center for the Disabled and the Chicano Federation, 1978	351

INTERVIEW HISTORY--Raymond Uzeta

Mr. Raymond Uzeta is a Mexican American from San Francisco who developed a severe disability as an adult, after he was married. He is one of a few members of an ethnic minority who were active in the early independent living movement in the Bay Area. His perspectives provide a revealing glimpse into his new life as a person with a disability, family expectations of him, and cultural attitudes about people with disabilities.

Ray's introduction to people with disabilities was at the Recreation Center for the Handicapped in San Francisco, the Indoor Sports Club, and the California Association of the Physically Handicapped--all of which he credits with the earliest grass-roots organizing for architectural barrier removal and with practicing the independent living philosophy before the Center for Independent Living in Berkeley was established. He developed the first transportation services at the Center for Independent Living, played an active role in the Section 504 sit-in in the Federal Building in San Francisco, and was the first director of the San Francisco Independent Living Center. Ray moved to southern California and worked at the Community Service Center for the Disabled and currently directs the Chicano Federation of San Diego.

One interview was held with Mr. Uzeta on October 11, 1998, in his home in San Diego. The interview was held sitting at the kitchen table with Connie Soucy, Ray's partner, observing the interview. Connie can be heard at times in the background, quietly commenting. The interviewer made small editing changes and corrections and the transcript was sent to Ray for his review. He made no substantive changes. The audiotapes are available for listening at the Bancroft Library.

The Regional Oral History Office was established in 1954 to augment through tape-recorded memoirs the Library's materials on the history of California and the West. Copies of all interviews are available for research use in The Bancroft Library and in the UCLA Department of Special Collections. The office is under the direction of Willa K. Baum, Division Head, and the administrative direction of Charles B. Faulhaber, James D. Hart Director of The Bancroft Library, University of California, Berkeley.

Sharon Bonney
Interviewer/Editor

February 2, 1999
Regional Oral History Office
The Bancroft Library
University of California, Berkeley

Regional Oral History Office
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Berkeley, California 94720

BIOGRAPHICAL INFORMATION

(Please write clearly. Use black ink.)

Your full name Raymond Robert Uzeta

Date of birth 5-20-41 Birthplace San Francisco

Father's full name Anthony Uzeta

Occupation deceased Birthplace Mazatlan, Mexico

Mother's full name Maria de Jesus Hernandez

Occupation retired Birthplace Mazatlan, Mexico

Your spouse _____

Occupation _____ Birthplace _____

Your children Anthony, Christina, Catherine, Carolyn, Shanda

Where did you grow up? San Francisco

Present community San Diego

Education M.R.A. University of San Francisco

B.A. UC Berkeley

Occupation(s) Administrator; non-profit executive

Areas of expertise non-profit administration; disability issues; Latino community issues

Other interests or activities _____

Organizations in which you are active _____

INTERVIEW WITH RAY UZETA

FROM DISABLED TO EMPOWERED: PASSAGE INTO DISABILITY, INDEPENDENT
LIVING AND DISABILITY RIGHTS

[Date of Interview: October 11, 1998] ##¹

Early Involvement with Bay Area Disability Groups: The Indoor
Sports Club and California Association of the Physically
Handicapped

Bonney: Ray, could we start out by you telling me where you were born and when?

Uzeta: I was born in San Francisco in May of 1941.

Bonney: Tell me a little bit about your parents and your family.

Uzeta: Okay. Both my parents migrated here from Mexico, from Mazatlán, back in probably the 1920s, separately, and they met here. They got married, and they raised--my mother gave birth to eleven children--nine of whom survived and grew up, and there's about six of us left. My father deceased back shortly after I was born in '41. My mother is currently ninety-three years of age and in a convalescence hospital here in San Diego.

Bonney: What was your childhood like?

Uzeta: What was it like? Nothing unusual. I grew up in the city, San Francisco. Went to school. Nothing extraordinary. My first elementary school was St. Paul's in San Francisco, for four years. Then the last four years, from the fifth to the eighth grade, went to St. Anthony's. From St. Anthony's I went to Riordan High School, and then I went to work.

Bonney: After high school.

¹## This symbol indicates that a tape or tape segment has begun or ended. A guide to the tapes follows the transcript.

Uzeta: After high school, right.

Bonney: Did you go to college?

Uzeta: Yes. I went to City College of San [Francisco]--well, I was out of high school for about ten years before I went to college--so my first college experience was City College in San Francisco, and from there I transferred to UC Berkeley. Majored in social welfare, got my B.A. there. Was out for about a year, and then I got into the master's of rehabilitation administration program at the University of San Francisco [USF], where I did my master's over there.

Bonney: What years were you at Berkeley as a student?

Uzeta: I think I was in Berkeley from '71 to '73.

Bonney: And then you got your master's--

Uzeta: In San Francisco, at USF.

Bonney: In '75?

Uzeta: Well, I started the program, I think, probably maybe in '75 or something when I enrolled, but it was kind of a very unique program, where there wasn't really a deadline to meet your master's. I forget exactly when I finished all the coursework for the master's degree. It was more like a program where you, I think you had, like, eight on-site semesters, but most of your stuff was work-related. We did projects that were related to your work. So it wasn't really a traditional--it wasn't like an academic program--where you spent all your time going to classes. You had, like, six sessions on site, on campus and then you went back to work. Took some idea and tried to implement it at your work site, so it was a more experiential kind of program.

Bonney: Now, were you born with your disability?

Uzeta: No, no, no, no, no. My first disability was diagnosed in 1960. It was diagnosed as a peripheral neuropathy. Later on they rediagnosed it as a poly-neuropathy, and they rediagnosed it as something else.

Bonney: Which means?

Uzeta: Who knows what. Basically, the peripheral neuropathy just means the neurological systems in your extremities, like your arms and legs or something, are impaired. So basically it creates a lot of

atrophy in my arms and legs, and weakness and impaired manual dexterity, which has been permanent.

The more serious disability was myasthenia gravis, which hit me in '65. That's really been the most devastating, from diagnosis around May '65 to fully incapacitated within three months. That basically knocked me out of the workforce for about ten years. That was really my real disability, my real disability experience. That really then got me exposed to other people with disabilities.

Bonney: Let's talk about that. You went to Berkeley as a student. Is that when you got involved at CIL [Center for Independent Living]?

Uzeta: Well, let me back up because I want to talk about CIL and real misconceptions. I just have to set the record straight. I got involved with disabilities issues when I became disabled--well, with myasthenia--in '65. Around '66 or '67--I forget exactly when--my first exposure to other people with disabilities was at a program called the Recreation Center for the Handicapped in San Francisco, by that time out near Fleishhacker's Pool. I think it still exists. Was started by one of these wealthy socialites, one of these do-gooders. So she set up this recreation program.

Big population of the clients were DD [developmentally disabled], but there was one group of people with physical disabilities. At that time, I was basically homebound, and so I needed some kind of outlet. Some social worker got me hooked up there. And that was my first exposure to other people with disabilities. I mean all sorts of physical disabilities, across the whole gamut.

Actually, that's where I met Bill Tainter, who I worked for for years here and became the director of the California Department of Rehabilitation. I met Bill and his wife at that time, at the recreation center, and a bunch of other people. From that exposure--that was really my first exposure to what CIL later coined the phrase of peer counseling to describe. Peer counseling was not created by CIL. I mean, the genius of the people at CIL was that they were able to articulate a philosophy which other people had practiced for years and to coin a phrase, peer counseling. Peer counseling came across way before CIL ever existed.

So that was really my first exposure to disability. Most of what we call independent living skills and knowledge and information I gained from people I met at the recreation center because there were other adult people with disabilities. From there, what happened is--because we had our brains--we really

didn't like the way we were treated. Basically, we were treated as cripples, objects of pity.

So those of us who were angry enough decided we're going to take on the administrator, which we did, and got our butts kicked out of there. Some of the people who we met at the recreation center belonged to another group called the Indoor Sports Club. The Indoor Sports Club has been around for eons in California and nationally. They had a whole statewide network. They had a whole national network. Predominantly people with physical disabilities.

I'll give you some people to find. You should really find them because they are some of the original advocates in California. The original people who went after the whole issue of architectural barriers were all Indoor Sports people who were concerned about legislative issues, who really did peer counseling, but they didn't coin it peer counseling.

And then, from Indoor Sports Club people--by that time--now we're getting into, like, the seventies. By the seventies, a whole lot of things started happening, such as Indoor Sports Club gave the initial seed money to what then was called California Association of the Physically Handicapped, CAPH. CAPH got started with a twenty-five thousand dollar loan from Indoor Sports Club. That's how they started.

So then you had Indoor Sports Club, who had been around for, like, thirty years. Predominantly a social group but also involved in--as a matter of fact, the first architectural access laws in San Francisco when I lived there was pushed by Indoor Sports Club people. They were the ones who pushed it. All those curb cuts you see down on Market Street? That did not come from CIL-Berkeley or the independent living movement; it came from Indoor Sports activists in San Francisco, people like myself and other people who formed different groups in there.

Then, in the seventies, two things happened simultaneously, almost simultaneously in the seventies. CAPH was born. CAPH specifically was incorporated as a 501(c)(4) political advocacy organization, membership organization. Then, within about three years, CAPH went from four people to five thousand members throughout the state of California and chapters all over the place. CAPH was the sponsor of the original architectural barrier removal laws at the state level.

That was all CAPH stuff. So the originators of CAPH, what they did, every two months they circled the state of California, basically doing grass-roots organizing. The rallying cry was

we're going to get rid of architectural barriers. People related to that, and so they went from zero to five thousand people very quickly.

So then you had CAPH, you had Indoor Sports going for years and years and years, predominantly a social support group, doing peer counseling, from the forties (people don't realize that), and then some interest in architectural barriers. Then you had CAPH started in the seventies. Got incorporated, specifically to take on architectural barriers, and eventually they hired lobbyists. All the access laws in California come from CAPH. And the lobbyists we had over the years.

Then you have over in Berkeley the start of the activists at Cowell Hospital. From them, people like [Ed] Roberts and John Hessler and a bunch of other people, we started getting together and really kind of rebelling against the medical model. But the rebellion against the medical model had already started in other parts of California. But people like Hessler and Roberts and other people, the students--I mean their contribution was that they were able to really, like I say, articulate a philosophy.

Then from there, that's how the disabled students' services [Physically Disabled Students' Program] got started, with Hessler as the first exec. Then from there sprung people who were saying, "Well, now that we got this on campus--this is great--but what about services for the broader disabled community?" Then that's where the whole philosophy of people with disabilities taking control of their own lives really got articulated. But it was already being practiced throughout organizations such as CAPH, Indoor Sports Club. A lot of other people were already practicing that philosophy.

But then Berkeley got started. Berkeley really--the people at CIL and, like, Phil Draper and Jack [John] Rowan and Berry--not Berry. I forget all these guys' names. Half of them are dead now. Their emphasis was anti-medical model and let's control the services. So they went down the path of providing services. So then you had Indoor Sports--the triangle--Indoor Sports doing the social activity stuff; you had CAPH really doing legislative advocacy around architectural barriers; and then you had CIL, who was really services-oriented with a big emphasis on IHSS [In-Home Support Services] and SSI [Supplemental Security Income], and taking on IHSS issues. So they kind of went down their separate paths. Then CIL finally started to grow, and it got replicated through statewide--when Ed became the director of Rehab--and then it went national when they got national money for independent living centers.

Volunteer and Employee at the Center for Independent Living, 1973-1976

Bonney: When did you go to CIL? How did you end up there?

Uzeta: I ended up at CIL because I went to Cal Berkeley, and when I was at Cal Berkeley--because I usually used disabled services at City College--so when I went to Cal Berkeley I looked for Disabled Students' Services. That's where I met Hessler. From Hessler, when I was getting ready to graduate, he said, "Have you ever heard of CIL?" I said, "No." He said, "You might want to check them out." I still at that time was on Social Security disability. I was living in San Francisco, really active in disabled politics in San Francisco. So I had some free time.

So I just called CIL one day. The first person I met there was Phil Draper and Don Berry, Don Berry. That's who it was. Basically I said, "Hey, I've got some free time. I can give you some hours of my time." And so they said, "We're interested in setting up a transportation system." So I went out, did research, wrote a grant proposal; it got funded, and Ed Roberts said, "Do you want a job running the program?" And that's how I got involved with CIL.

Bonney: Tell me about transportation. Why was it important at that point in time?

Uzeta: Well, because at that point in time there was no--first of all, we didn't have any transportation legislation back in '73. I forget when that happened, '74 or '75. No buses were wheelchair accessible, so the alternative was either let people stay in their homes or set up a para transit system. At that time, CIL chose to set up its own para transit system. We started with one, two, three, four vehicles.

Bonney: Who funded those vehicles?

Uzeta: Those were CalTrans. The vehicles were CalTrans purchases. That program still exists. I forget what the name of it is. Operating money, I forget where we got the operating money from. That was harder. That was the hardest money to find, and it paid salaries and gas and a lot of good stuff.

Bonney: Who rode the buses?

Uzeta: Basically, once the word got out, people with mobility impairments. Our target population were people with mobility

impairments, both seniors and non-seniors. Once the word got out, it just mushroomed.

Bonney: Did seniors use it?

Uzeta: Yes. I forget what the percentages were, but it was both used by both seniors and non-seniors. A lot of wheelchair users took advantage of the service.

Bonney: Do you remember the number of rides you gave in a month?

Uzeta: Oh, no. That was a long time ago, a long time ago.

Bonney: Who were the drivers?

Uzeta: The names?

Bonney: Yes.

Uzeta: Oh, I can't remember who they were. There were quite a few drivers.

Bonney: Now, the transit system remained in operation while you were at CIL?

Uzeta: Yes.

Bonney: And at some point you became a staff person and not a volunteer. How long did you volunteer?

Uzeta: Well, I started working for them in '74, so from '74 to '76 was when I was at CIL.

Bonney: That's when you were a staff person.

Uzeta: Yes. Right, right, because I worked under Ed and then Ed left and became director of Rehab, and then I worked under Phil [Draper].

Bonney: While you were there under Ed and under Phil, how did policy and administrative issues get resolved?

Uzeta: Good question. See, I had no interaction with the board of directors, so I really don't know. I would assume probably by--Ed and Phil were the leaders--and that kind of stuff. But CIL was interesting [chuckling].

Bonney: What do you mean by that?

Uzeta: Because at that time, when it started, it had the great egalitarian philosophy of Berkeley, where it was a membership organization, so all the members elected the board. Basically what happened--usually what happened--a faction on staff basically got pissed off at the exec, they'd go off and recruit people to become members. Then there'd be an election and they'd elect their board, their buddies to be on the board, right? And there would be this big upheaval.

I remember once when Phil was the exec, and there were some board members who really were wanting to force him out and had some policy decisions which Phil disagreed with. The directors made this policy decision, and Phil said, "I'm outta here." And about 90 percent of the staff said, "We're outta here with Phil," and we all walked out of the building. Of course, the board members who were there in the room kind of crapped in their pants and then reversed themselves. But that's how political it was.

That was the flaw in that whole structure. What happened--every other center that started after CIL in the seventies--used CIL as a model, and they all did the same thing: became membership organizations. In retrospect, after a while, people got rid of that. They realized that was a big, big mistake because it was too subject to political abuse by staff.

Bonney: As an employee, what was the atmosphere like at CIL?

Uzeta: CIL was a great place to work at. In the seventies it was a lot of fun, very exciting. When I came to CIL, it was on University Avenue on the second floor. I was there the day the elevator caught on fire, and the firemen freaked out because they had to carry all the people in power wheelchairs downstairs, people like "lightweight" [Michael] Pachovas [laughing]--who weighed 700 pounds. Hale Zukas was caught up in the building. I think Kitty Cone was in there. A bunch of other people. I was on a lunch break. I found out about it. Anyway, the fire department totally freaked out and gave Ed--Ed was the exec at that time--and gave Ed something like sixty days or forty-five days to get out of the building. That's when they bought the building where they're currently at because they were forced to move from University Avenue.

But CIL was an exciting place. It was fun to be at. There was always something exciting happening. One of the ways that Ed grew the organization is that if someone walked in off the street and said, "I have an idea," I think his philosophy was, "Go find some money for it, and you have a job." I think that's really how a lot of CIL grew. People went out and hustled and got grants, and the place just mushroomed.

When I left, God, I think--well, I started in '74, there were about twenty people on the staff. I shared a room with Kitty, Hale and Eric Dibner; they were my office mates. Ken Stein was also there at the time. Then when I left in '76, there must have been fifty, sixty people on staff by that time, when I left. And then it grew larger afterwards, yes.

Bonney: How did CIL manage this organization that kept getting bigger and bigger and bigger?

Uzeta: I can't respond to that because I basically ran my department and that was it. I don't recall ever having, like, manager meetings or administrative meetings. Basically I think both Phil and Ed just worked with managers one on one versus bringing all the administrative people together and working as a team.

Bonney: Okay. While you were at CIL, were you there for some of the financial crises that went on?

Uzeta: There's always a financial crisis.

Bonney: What was that like? How did it affect you?

Uzeta: Well, I don't think my department really got affected. I think the major financial crises may have happened after I had gone. I don't recall any big financial crisis. When I was there, we were in a growth mode. We weren't in the shrinkage mode when we had all these federal cutbacks. That was after my time. But I know how that affects people because when I worked at Community Service Center for the Disabled down here in San Diego for ten years, we went through a lot of those financial crises, and I know what happened there. I would assume the same thing happened at Berkeley.

504 Sit-In, 1977

Bonney: You were there, I think, for the 504 sit-ins?

Uzeta: Yes. No, I was in San Francisco then. I started the ILC [Independent Living Center] in San Francisco in '76. So I was in San Francisco for the 504 sit-in.

Bonney: Now, you were in the building.

Uzeta: Yes. Now, what part do you want to know about it?

Bonney: I want to know everything about it. [mutual chuckling]

Uzeta: Not everything. Some of it is censored [chuckling]. Judy [Heumann] called me one day. By this time, I was running the ILC in San Francisco. She said, "We're going to have a meeting." I said, "What about?" She said, "Well, there are some federal issues coming down." So a group of us met over at CIL. Judy at that time was telling us about the 504 regulations and I think it was ACCD [American Coalition of Citizens with Disability], whatever, was calling for a national boycott because of the rumor that the [President James] Carter administration was going to water down the regulations.

So Judy said, "We're going to go do a rally in front of the federal building. We might sit in, but if we do, it will only be for a couple of days." We all said, "Oh, okay, Judy, whatever you want." So we had the rally, and everybody gave all their little speeches, and Judy gets up on the podium and says, "We're all going to go into the building because we want to meet with this guy [Secretary of Health, Education and Welfare Regional Secretary Joseph] Maldonado."

All I recall is this surge of people going through the building. As a matter of fact, Connie [Soucy] was there by this time--this surge of people go into the building, go up the elevators, and by the time I get up to the fourth floor, I walk into Joseph Maldonado's office. This guy was surrounded by people in wheelchairs. So this guy is sitting at his big desk, and Judy was there, pounding on the desk, saying, "We want you to call [Secretary of HEW Joseph A.] Califano right now." So he called back there and tried to get the secretary, and he was out.

Pretty soon, this guy gets into a dialogue. Judy was asking him all these questions. He said, "Well, let me call my staff up here, right? Because I really don't have the answers." So he called all his deputy sec and regional people up there. Judy would ask them questions, and these guys were basically unable to answer and I remember she leaned over the table, and she says [hitting table], "I should have your job because you guys don't know what the hell you're doing." [laughing] It was ironic, because now she's their boss [laughing]. I remember that. She said, "You guys don't know what the hell you're doing. I should have your job." They couldn't answer questions about the regs. They could answer nothing.

Anyway, it got real close to five o'clock, and Mr. Maldonado says, "Well, I want to go home." Judy says, "Fine. We're staying." So he got up and walked out of his office, and we all followed him to the elevator, chanting, "Sign 504." He went down

the elevator, and we all stayed. We stayed there for whatever we stayed there for.

Bonney: What was it like the first night?

Uzeta: First night was really interesting. Nobody really knew what to expect and what was going to happen. People thought, "Well, we're here to stay." We figured, "What do we have to do?" And "Where are we going to stay at?" And "What's going to happen next?" I don't think anybody was scared about anything the first night. People were kind of too hyped up about what we were doing. We said, "Hey, now we're going to stay here till this thing gets resolved."

Bonney: What did you see Judy doing?

Uzeta: Well, Judy was the key leader. She really was the organizer, the spokesperson for the whole thing. What happened after it became apparent that we were going to be there for more than forty-eight hours [chuckling] is that we got organized very quickly. What started happening is, like, Connie here was in charge of medical support staff. Somebody else--Jim Pechen, I think, was in charge of security or PR [public relations].

So there was, like, a security committee, a PR committee, there was a medical support committee, there was a food committee, they had a press committee. So it was very structured. Every night the steering committee, which Judy was the leader of, would get together and figure out literally day by day what activities were going to be for the next day. You know, who talks to the press, whatever.

It's very interesting how the San Francisco community responded very rapidly, especially other organizations who started delivering food. Black Panthers brought stuff there. Safeway Inc. donated food. After we were there for a while, former Mayor [George] Moscone came into the building to see us, and he arranged to have mattresses brought in, I think from the National Guard armory or something. Somewhere along the line, Leo McCarthy, who was lieutenant governor, came by to visit us. Eventually, Judy managed to get what's his name? Congressman George Miller and John Burton to hold congressional hearings inside the building.

But then what was really exciting to us who were inside of it was that every night on Channel 7, KGO-TV, the lead-off story was the sit-in, every day. So that was a real hype for those of us inside the building. It was really exciting to be inside the building.

Bonney: Tell me, how did the hearings come about that George Miller and Burton--

Uzeta: Well, I think that's because of Judy's political advocacy because Judy was always on the phone, organizing the external. She had enough smarts to know that nothing was going to happen with us sitting inside the building. The pressure had to come from Congress. She and I'm sure other people outside--and I don't know who they were because I wasn't in that circle--organized that.

Then eventually the decision was made to send a contingent back to D.C. That was the worst part because when Judy, Kitty Cone and about twenty people left the building--Judy left me and somebody else in charge of the building--the mood really changed. People really started getting very uneasy all of a sudden and very panicky. But they went back to D.C., and we kept track of what they were doing. She was calling every night to see how it was going. You know, we stuck in there.

Bonney: Why did people get panicky?

Uzeta: Well, I don't know. I guess because they figured Judy wasn't there, right? Because up to that point, I mean, it was exciting, but I think people were stressed a little bit anyway at the same time. Not knowing one day to the next what was going to happen. I think that if Judy by herself would have gone, it would have been okay, but Judy and Kitty and a whole bunch of people left. Probably people weren't sure what was going to happen or whether--it could have been maybe people were fearful that maybe the feds were going to come in and kick us all out or the cops and everybody was going to get busted. Who knows what the fear was? It was never really articulated. But it was real traumatic, the change in mood. It was real noticeable.

Bonney: How did decisions get made among that group of people?

Uzeta: The left-behind?

Bonney: Well--

Uzeta: The whole group?

Bonney: The whole group before they were left behind.

Uzeta: Like I say, basically Judy and there was like a steering committee. They had their meetings, and they made all the decisions.

Bonney: And then told the rest of the group what was happening?

Uzeta: Yes, basically. Or told what the group needed to know, probably.

Bonney: And then when the group left and went to Washington, what did you do? What did you have to do?

Uzeta: Well, basically, to chair the meetings. We usually had the groups together, to keep people apprised of what was going on. You know, making sure that, you know--all the medical supplies and the food--basically that the logistical things were taken care of. Basically, to hold the fort down. That was my job.

Bonney: Were there medical issues?

Uzeta: Oh, I don't know. Yes, Connie says yes, there were. I didn't deal with them directly, but I'm sure there was. Like for example, I'm sure somebody had disreflexia while they were in the building. You know, getting proper attendant care for people.

Bonney: Can we go back to the Burton hearings for just a minute?

Uzeta: Yes.

Bonney: What was it like while those were going on? And who came and testified?

Uzeta: Well, I was mostly outside in the corridor. But basically it was a lot of people with--

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Uzeta: --all those things have a really uplifting, positive effect on people because when Burton was walking through and a lot of us were in the corridor, what he said to us, he says, "You're doing the right thing. Stay here." What was happening at the same time, now that you bring this back, there were a lot of people on the outside. The other thing that was happening during the whole sit-in is that on the outside a lot of our supporters were having rallies which were basically supporting what was going on inside.

We picked all this up on the news. So we knew not only were we on the inside putting basically our bodies on the line, we also knew through the media that we had these outside supporters. A lot of the people who for the most part sat on the sidelines, on the fences, came off the fences and came for rallies. Those things were really encouraging for people who were on the inside. It really helped motivate us and keep us going. We weren't really alone.

That's really the importance of people like Burton, who came in; McCarthy, who came in; Moscone, who came in. It was really that moral support that helped us. It really carried through in staying there.

Bonney: Now, I know that there were many inconveniences while you were there. How did people cope with that?

Uzeta: I never noticed. Well [chuckling], see, for me--actually-- [chuckling] I'll tell you the story now. I had an apartment nearby, so every once in a while I'd go home. I was one of the few people who had a regular hot shower. For everybody else, it was tough. It was tough, because there were no showers. Matter of fact, I kid people that next time we do a sit-in, we'll make sure there's hot showers. So a lot of people went without bathing. Eventually, they brought in literally, like, this little what do you call these things? Like plastic swimming pools? They'd get people, transfer them onto a chair inside this pool, and then they had these hand-held showers, hand-held hoses that plugged into the bathroom faucets, and that's how a lot of people took showers. That was really, I'm sure, uncomfortable for people.

What started happening as far as the accommodations, people started to break into groups. You'd have, like, for example, some of the gays and lesbians, they'd have their quarters. Others of us had our quarter. I had my quarter, in fact, somewhere. People selected out their roommates and people would share their sleeping--some people slept right in the corridor--on the mattress. That was their spot. But everybody found kind of their spot for sleeping.

The meals were really organized. I forget the guy who it was. But we took Maldonado's office. He had an air conditioner there. So this guy got some cardboard and plastic and put it around the air conditioner, and that became our refrigerator, so all our dairy products, perishables, were in the refrigerator. Maldonado's office became our kitchen, like. We had [laughing]--people would come in one door, pick up their food [chuckling] and go out the other door.

Bonney: Did Maldonado come to work every day?

Uzeta: Oh, no, no, no. He moved offices. As a matter of fact, what the feds did--they were very accommodating because they didn't know what the hell to do with us. They literally gave up half of the fourth floor. They gave it up, turned it over to us. The only thing they really did was have security people kind of tour--but

after a while, they kind of--they were okay, the security guys, yes.

Bonney: Did you all party?

Uzeta: Best parties in my life were in the building.

Bonney: Tell us about some of those.

Uzeta: Well, we had two nurses. One was Sue [Susan] Knight and her friend--I forget who her friend was--who are nurses. And so every day they would bring in liquid refreshments. They were able to get by security. I would say there was definitely a party every night. I was the chief party giver [laughing]. I would say there were some nights when some of us got quite intoxicated, feeling really great, yes. Actually, that certainly helped pass the time.

Bonney: What was your reaction when the regs were signed?

Uzeta: It was pandemonium. It was really a tremendous emotional rush. People were running around yelling and hugging each other. It was really a big rush, yes.

Bonney: And did you all leave right away?

Uzeta: No.

Bonney: Why not?

Uzeta: Because after they finally got signed, we all pulled back together to our planning room and said, "Well, now what are we going to do?" So we decided to have an orderly exit. Actually, I think we stayed for about two or three more days before we actually left. We made the determination that before we leave, we're going to clean the place up because we knew we were going to get all this negative crap from the media. So we cleaned the place up as best we could, and we said, "we're going to march out and hold one final rally." So that's when Senator Milton Marks joined us. We left the building, and we had the rally.

Actually, that was rather anti-climatic. Once the rally broke up, it was like, "Now what?" I mean, as long as you're inside the building, you were bonded. You were bonded. The minute you went outside--once we left that building, once the rally was over--it was, like, people stood around, like, "Well, now what do we do?" [chuckling]

Bonney: "Where do we go now?"

Uzeta: Yes, exactly. The war is over. What do you do?

Bonney: Did Judy and the other contingents that went to Washington come back to the federal building?

Uzeta: I forget. That's a good question. I forget whether they were back. I don't remember them being back at that final rally, when we did the exit, yes. So they must have still been in D.C. when the regs got signed.

Disability as a Civil Right and Contributions of Leaders

Bonney: Okay. Let's change focus just a little bit. When did you first see disability as a civil right?

Uzeta: Probably in the mid to late sixties, yes. That's because of my exposure to other people with disabilities. Definitely by the early seventies, when I joined, like, CAPH.

Bonney: Were there specific incidents or things that sort of raised your consciousness about it?

Uzeta: Well, just being around other people with disabilities. You know, hearing people's frustrations: the issues of discrimination, not being able to find a job, being treated differently from other people. At that time I used a wheelchair, and I became really aware how people, ABs [able-bodies] treated disabled people. So it was a real consciousness change and experience.

Bonney: When you were at Cal, did other social movements influence you?

Uzeta: Me personally? No.

Bonney: No? Free Speech, Vietnam, none of that.

Uzeta: No, none of that stuff really had any influence on me.

Bonney: Why do you think that the Ed Roberts and the John Hessler and the people who started DSP and then CIL were the people who did it? What was it about them?

Uzeta: I don't think it was those people per se. You could have taken those kinds of people anywhere and started it. I think it could have been they were on the Berkeley campus [when] the Free [Speech] Movement and all that civil rights stuff was germinating and coming to the forefront. Berkeley has always kind of been in

the forefront of stuff like that. So I think it's really accidental.

Quite frankly, you had a small group of people in a contained area called Cowell Hospital. They were forced to interact. Probably you didn't have that situation in a lot of other campuses where you had a medical facility. You know, one might say if Cowell Hospital were never there, would DSP ever come to fruition? Probably so, a little bit longer.

I remember once my friend, Phil Draper, and I were having a big discussion once about Berkeley. As a matter of fact, we asked ourselves the question, "Why did it start in Berkeley versus why not San Francisco? Why not Los Angeles? Why not Chicago? Why not New York City?" Phil said, he thought about it, and he said, "Well, perhaps the reason is because Berkeley is so geographically small that it was very easy for people to meet one another."

I think there's a lot of truth to that. We don't think about that, but if you go to, for example, some place like L.A., which is so spread out, even today, you cannot organize people because of the geographic space, whereas Berkeley was a very contained geographic area. The people were able to get together very easily, very easily get together and start thinking and philosophizing and organizing. And there's probably a lot of truth in that. That's one of the reasons that made Berkeley happen. I don't think it could have happened anywhere else. Or at least not in a major city geographically spread out.

Bonney: What's your take on the idea that Ed Roberts is the father of the independent living movement?

Uzeta: I think a lot of people, no. Well, he's not the father of the independent living movement. I think if you ask people who were there, who really started the whole independent living philosophy, it wasn't Ed. I mean, Ed was just one of several people, people like Phil Draper, people like John Hessler, people like Don Berry, a lot of other people.

The contribution Ed made--that's why people make this mistake--was he was the first person who really had a charisma to articulate the philosophy to the broader community. That's really Ed's contribution. But he's not the person who came up with the idea. I doubt if he were here he would even say he's the one who came up with the idea. I think it was several people coming together and articulating stuff. Ed was a messenger, and Ed had a charisma and was able to bring it to the broader community. That really was his unique contribution and trait.

See, Ed was never a good administrator. I've been in nonprofits for twenty-five years now. That's not a criticism of Ed. I watch people in the nonprofit movement. I work with the Latino community, so I don't care if it's the Latino community, I don't care if it's the black community, I don't care if it's the disabled community. When it comes to administration, there are two people: one's the advocate and one's the administrator. I've never seen anyone who's good at both of them. You're either a good advocate, or you're a good administrator. Ed was a good advocate, right. And good spokesperson.

Bonney: What was Judy's contribution? What is her contribution?

Uzeta: Judy also is a good advocate, a good spokesperson, very articulate person. I mean, Ed brought Judy in, actually, Ed brought Judy in from New York, and there was a lot of resentment against that, really a lot of resentment.

Bonney: Why?

Uzeta: Because he brought this outsider into the organization. But it smoothed out over a while. She kind of earned her way here in California. But Judy is like Ed: very articulate, really understands the whole civil rights stuff, very political, very political.

Establishment of the San Francisco Independent Living Center, 1976

Bonney: Let's talk just a little bit about when you left CIL. You went to?

Uzeta: San Francisco.

Bonney: San Francisco. And you did what?

Uzeta: I started the ILC in San Francisco which at that time was a joint project of United Cerebral Palsy Association. The exec at that time was John King. John who has since deceased. So it was the joint project of United Cerebral Palsy Association [UCPA] and the local chapter of CAPH, were the sponsors of the organization. But it was under UCPA's fiscal control because they were the nonprofit incorporated entity.

But even from day one, the plan was--and I think the San Francisco center started with an Innovation and Expansion grant for three years--so the plan from day one was always that once the

federal grant was over that the ILC would incorporate as its own entity.

Bonney: Was the ILC of San Francisco part of the move to create ILCs across the state under Ed Roberts as director of DR [California State Department of Rehabilitation]?

Uzeta: No, no. There were about six or seven programs, and all got started more or less at the same time. First of all, you had Ed. Ed became the DR director in '75. But I think it was '76 when the I&E grant, the first wave of I&E grants became available. At that time, I think Sacramento, San Francisco, San Diego, West L.A., Los Angeles, maybe Orange County and one other area all got started--no, not Orange County. Anyway, Fresno got started. There were, like, six ILCs that got started in '76, with the initial I&E grant.

Bonney: From DR.

Uzeta: From DR. Ed was committed to doing that. Then maybe in '77 was the second wave of ILCs that got started, yes. So San Francisco was in the first wave.

Bonney: What was your motivation to write that grant and make this happen?

Uzeta: Well, because I'm a San Franciscan, right? I was the president of CAPH. I was involved with all these disability groups in San Francisco, basically one of the key disability leaders in the city. I knew there was going to be this movement to start it. I got involved with helping start the ILC.

Bonney: What did it do? What were its first services?

Uzeta: It was modeled after CIL in Berkeley. We had attendant care and benefits advocacy. When we pushed it on the UCPA, UCP also had an employment program and also some kind of health-related program going. What John was trying to create was a multi-purpose center. So UCP was one component, the employment was another component, the health thing with Susan Knight was another one, and then the ILC.

Within the ILC we did--I just mentioned to you--we did attendant care stuff, the financial benefits stuff. I forget what, oh, we also had an independent living skills trainer in there. We tried to start a small wheelchair repair business. Those were, like, the first four programs that we started, services.

- Bonney: Did you also work on issues, political issues or problems in the area?
- Uzeta: Well, we no longer started a program then we were all in the sit-in [chuckling], yes.
- Bonney: How long did you stay it the ILC?
- Uzeta: I was there for two years.
- Bonney: And you left?
- Uzeta: And I left there and came to the ILC in San Diego.
- Bonney: To do what?
- Uzeta: To work for Bill Tainter and [Raymond] Zanella. Basically, I worked on doing their community advocacy stuff.
- Bonney: Bill Tainter and who?
- Uzeta: Ray Zanella. And they're both deceased now. Scary.
- Bonney: Yes, a lot of people are gone.
- Uzeta: Yes.

Comments on Life as a Minority Person with a Disability

- Bonney: Let me ask you sort of a personal question. There aren't very many Hispanic people very active, visibly active in the disabled movement, whatever you want to call it. What are your opinions about that? Why is that so?
- Uzeta: I think it's cultural. I think the same is true of Asians. You're not going to find many Asians there because I think historically both Asians and Hispanics keep people with disabilities as dependent, to be taken care of, keep them in the closet.
- Bonney: Is it still that way?
- Uzeta: Probably I think to a large degree, yes. I mean, even down here, as involved within the Hispanic community as I am in my job, I see very few Hispanics with disabilities. I go to the largest Hispanic organization in the country in our conferences, and I've

never seen in our conference one Hispanic wheelchair user, never. I get exposed to five thousand people [chuckling] at a conference, yes. Yes, I think a lot of it is cultural stuff.

Bonney: What is it about the culture? Why are they just sort of kept hidden, as you say?

Uzeta: Well, I think it is basically someone to take care of, the whole idea that you could do something is a foreign concept. You've got to remember that here in the United States the Hispanic population has changed tremendously where the majority now are immigrants, recent immigrants, a lot of them, in the last ten years. They come from Mexico, they come from Central America, where you don't have access, you don't have social services, you don't have the medical support system.

In those poorer countries, people with disabilities are kept down, yes. There is no expectation for them to go on to be a contributing member of society or to work or go to school. That's not the expectation. That's not the norm. So that stuff carries over on people who come to this country.

I suspect that you will find the same within the Asian community, yes. But even for African Americans, you don't see that many involved.

Bonney: But more.

Uzeta: But more.

Bonney: Yes.

Uzeta: But more.

Bonney: I can only name you and Felix Gutierrez in Berkeley, and that's all I know. And I think there was a woman who has since died.

Uzeta: Yes.

Bonney: And that's it.

Uzeta: Right.

Bonney: How did you get involved? Did your family--

Uzeta: With what?

Bonney: With the disability movement. Did your family just assume that you were going to do it?

Uzeta: Oh, no. No, no, no. I told you what happened to me. When I had the myasthenia, I was knocked out of the workforce. At that time, I was married. I guess I was driving my wife at the time crazy [laughing]. She was trying, I guess, to get me out of her hair for a while after a social worker--. That's how I got hooked up with the Recreation Center for the Handicapped. Once I got hooked there, that's where I got exposed to a lot of people with disabilities for the first time in my life.

And then from there, there were those of us who were rowdy, and then we migrated over into Indoor Sports Club. We met other people. So our network, our acquaintances expanded. Then I met the people at CAPH, and I got involved with CAPH, right?

Bonney: So for you, when you became disabled, you weren't cloistered in the family.

Uzeta: Correct. Yes, when I became disabled I was, like, twenty-five years old or twenty-one. Nineteen sixty-five. Yes, that's about twenty-five. So I was married and out on my own. See, I wasn't a teenager living at home. I just got exposed to other disabled people.

College Studies and Attitude Changes

Bonney: Could you tell me how being at Berkeley and being at CIL and just the whole milieu of that era and that area, how did it affect you personally?

Uzeta: I don't think it was being in Berkeley per se. I think becoming a person with a severe disability affected me because prior to that my family expectations of me were to basically finish high school and get a good job. Getting a good job meant getting a union job and that was it. That was the only expectation.

What happened--actually, when I got exposed to people in the recreation center--one of my buddies there said--he knew I was having all this family conflict--was, "You need to do something." He said, "Why don't you go to college?" I said, "What for?" He said, "Do something for the college," right? He was going to City College, and he had a real severe disability. He had osteo--what do you call it? Osteo imperfecta?

Bonney: Yes.

Uzeta: Right. So he was going to college. Really, he's the guy, Skii Leach, who also is deceased, was the guy who motivated me to go to college. I said, "Oh, I don't know if I can do this. I've been out of school for ten years." I was twenty-eight years old. So through my DR work, my DR counselor paid tuition, so I decided to go to City College. I took six units. The first day at campus, I thought it was the high school field day, and after about a week I realized, "Oh, my God, these are the students here at college!" [chuckling] Because I was ten years older than a lot of them, right?

So I took six units. Actually, that was really good for me, for a lot of reasons. After I took six units, I said, "Oh, this is a piece of cake," and I took nine units. I did real well academically. I had nothing else to do with my time, right? Except to study.

Bonney: Yes.

Uzeta: Then I took twelve units. At twelve units, this is fine. It keeps me busy, and I don't have to kill myself. So then I started going to college--City College--took twelve units there. By this time, I was getting involved with CAPH, so I had my disability advocacy stuff going on, and I had my network within San Francisco.

Then I decided, Oh, well, like a lot of people with a disability, I want to be a social worker, right? [Laughing] So I'd write to Cal, got accepted, and majored in social welfare. After I did my senior year at Cal, upper division, I had to do field placement. I thought I wanted to be a medical social worker, work with people with disabilities. So I did my field placement at Highland Hospital in Oakland.

I discovered very quickly, very quickly, that holding the people's hands and solving their problems was not my cup of tea. That's when I decided what else is there? But I was thinking of going for my MSW [Master's in Social Welfare] and actually applied for an MSW. I decided I was going into administration. I ain't this counselor-case type, you know, hold your hand, make you feel good type of person. I discovered that very quickly once I started the fieldwork.

But I still wanted to stay in the field, so I said, "Well, I'll go to administration, where I can impact policy." I said, "Well, hell, I can affect a lot more people doing that. So anyway, that's--"

Then Jeff Moyer, who was at CIL at the time, told me about this program at USF. He said basically, "Don't go to an MSW; go to this program at USF because it's more related to what we do in disability. Disability specific." I said, "Well, that sounds good," you know? So then I applied for the program at USF and got my master's over there, instead of my MSW, yes.

But anyway, becoming disabled--I lost my track--see, what it really did for me--prior to that--I was on the track of my family and all the people I grew up with. I was racist, I was bigoted against everybody else in the world, and once I became severely disabled because of my experience in this, realizing, "Oh, my God. People are treating me differently now than they did before." And "God, all these other things that happen to people through no fault of their own."

So really, between the disability and going to college and getting exposed to other people with disabilities really changed my attitudes toward society and other groups, yes, where I became a lot more tolerant, yes.

Bonney: It happens, doesn't it?

Uzeta: Yes. I came out more tolerant, yes.

Move to San Diego: Community Service Center for the Disabled and the Chicano Federation, 1978

Bonney: So you came down to San Diego to work in the ILC here, doing advocacy?

Uzeta: Yes, yes. Had a lot of fun here. It's a good experience. I learned a lot.

Bonney: And did that for about how long?

Uzeta: I worked for Bill and Ray for ten years. As a matter of fact, when I came out here, one of the things I did I set up a 504 [Section 504 of the Rehabilitation Act of 1973] compliance unit. We went around and filed 504 complaints. We also did training. As a matter of fact, we did training for the county and with their contract agencies around 504 compliance.

I had the fun part because, once again, I didn't deal with clients. So I had a 504 compliance unit and we had a component to run around [and provide] technical assistance for architectural

barriers. The newsletter came out of my department. So I had a lot of fun. Got to travel a lot. Yes, a fun time.

Bonney: And then what did you do?

Uzeta: Well, what happened in CSCD [Community Service Center for the Disabled] and same thing that happened at Berkeley is the funding cutbacks started happening, both at the federal and state level. That created a lot of internal tension. We had what I call the great civil war in CSCD at the time where people were being negatively impacted. Basically disgruntled staff blamed the administration, so they went off and organized and got a bunch of people as members. They had a special board meeting. Tipped the balance of power on the board of directors by one vote. The board fired Bill.

So Bill did a counter-revolution and went out and signed up a hundred new people, called a special board meeting, and basically purged the entire board of directors except for his allies. About a couple of months later, they changed the bylaws where it was no longer a membership organization. That's what I'm saying, a membership organization was great in theory, but democracy has its limits. It was open to abuse.

That's what happened in Berkeley with CIL. Not only in Berkeley. It happened in San Diego. Doug Martin in L.A. will tell you the same thing happened at WCIL [Westside Center for Independent Living]. So really what happened is the staff people used that to manipulate who got elected to the board because of their own self-interest. So eventually all the ILCs eventually got rid of that whole membership concept where the board became self-sustaining.

Anyway, somewhere along the way I knew I was burning out, and it was time for me to move on. Then a buddy of mine in Modesto, Manuel Gonsalves, recruited me to apply--they were just starting an ILC there, they got funded--to come up there. So I applied for the job, went there for three months, discovered very quickly, within about a month, that they had a brand new board of people who really didn't know what they were doing. A lot of AB types also.

After about three months, I knew this wasn't going to work, so very politely told them--

##

Uzeta: Anyway, so after about three months, I knew that wasn't going to work. Came back here. I really didn't want to go back to CSCD.

I wanted a change. What happened, Bill called me and he says, "Irma Castro is looking for an assistant director." He said, "It's right up your alley. I've got a job announcement." I knew Irma because she and I served on a city commission together. She was the executive director for the Chicano Federation [of San Diego] at the time.

So he mailed it to me, and I called Irma, and I said, "I'm back in town, looking for a job." She said, "Come by. Tell me what you're up to." So I went by and shot the bull with her, and then I applied for a job and got interviewed by her and two of her board members. She hired me as her assistant director in 1989.

I thought Irma would be there forever. My intent was just to be there for a couple of years. At that time, Bill Tainter was still the director of CSCD. I knew that Bill was going to be appointed by [Governor Pete] Wilson. By this time, I was on the board of directors for CSCD. So once Bill got the appointment, I told the board, at CSCD, "I'm going to apply for Bill's job."

At the board meeting, I said, "I'll have to excuse myself when we talk about that." So I actually applied. Then what happened, when Irma left the Chicano Federation, she announced her departure in April of '89, and when the board first announced her job, I wasn't interested in it because I was having my eyes out for Bill's job once he left. So I did not apply for the job.

Then the board reopened the job at the Chicano Federation, and one of the execs I knew at the time said, "Have you applied?" I said, "No." He said, "Why not?" I said, "What for?" I forget what he said to me, but basically, "It's a bad reflection on you if you don't apply." Something along those lines. It would be a bad reflection. So I said, "Oh, okay."

So I applied for the Chicano Federation job, not being serious at all. Then the next thing I knew, they invited me in for one of the finalist interviews. I figured, Well, yes, they're just being courteous to me because, meanwhile, I'm the interim director. I'm holding the place together. Next thing I knew, they offered me the job.

In the meantime, when I left San Francisco in '76--I had been ten years in San Diego--I continually, over the years, had been applying for jobs at other ILCs, and I would never get them. Job where I knew I had more experience and was better than the people they hired who basically screwed the agencies up. So when the federation offered the job, I said, "Well, I could either take

this job or gamble on the CSCD job." I said, "Well, history being what it is, there's no guarantee I'll get this job [with CSCD]." So I accepted the job, and I've been there ever since.

Bonney: Basically, what do you do? What does the federation do?

Uzeta: The federation is very much like ILCs. It's an advocacy and it's a service organization. We have childcare services. We do diversion programs for youths--you know, gang kids--do family counseling, case management for adults, how to find jobs. We do housing development. We have six pieces of property with 177 units. We buy properties and basically convert them into affordable housing, refinance and lower the rents. We have six properties. We have a senior center. We have leadership training programs that run sixteen weeks for communities of color. And we run a daycare center also now.

But most people know the federation for its political advocacy because it grew out of the sixties also. Was incorporated in '69 as a civil rights organization and as a federation of organizations basically dealing with equal opportunity, civil rights, social justice issues. The organization has a history of political advocacy and has litigated against the county and takes positions on state propositions like 209 and 227.

It's really the only organization locally, Hispanic organization, that speaks out on public policy issues, so it makes it very unique from other nonprofits. Other Hispanic organizations never take a political stance on anything. We do. So people either hate us--they either love us or hate us. There is no neutrality toward us, yes.

Bonney: Well, Ray, is there anything you'd like to say that I didn't ask you about, anything you want to talk about?

Uzeta: No, not really. But yes, my primary objective is to set straight the record that the independent living movement did not start in Berkeley. It really started way before--really way before that. A lot of other groups that are out there, a lot of other people were involved. As I mentioned to you, they were just fortunate. They were the ones who were able to articulate it. What other people had already practiced, they were able to put into a philosophical statement. And then to market it, market the whole concept of peer counseling, which had already been practiced by a lot of people in northern California and elsewhere.

Bonney: Okay. Well, thank you very much for letting me come and interview you.

Uzeta: You're welcome.

TAPE GUIDE--Builders and Sustainers of the Independent Living
Movement in Berkeley, Volume IV

INTERVIEW WITH JANET BROWN

Date of Interview: March 13, 1998

Tape 1, Side A	1
Tape 1, Side B	14
Tape 2, Side A	26
Tape 2, Side B not recorded	

INTERVIEW WITH PHIL CHAVEZ

Interview 1: March 24, 1997

Tape 1, Side A	33
Tape 1, Side B	43

Interview 2: April 7, 1997

Tape 2, Side A	51
Tape 2, Side B	59

INTERVIEW WITH FREDERICK COLLIGNON

Interview 1: January 29, 1997

Tape 1, Side A	72
Tape 1, Side B	84
Tape 2, Side A	96
Tape 2, Side B not recorded	

Interview 2: April 2, 1997

Tape 3, Side A	107
Tape 3, Side B	118
Tape 4, Side A	130
Tape 4, Side B not recorded	

Interview 3: September 17, 1997

Tape 5, Side A	138
Tape 5, Side B	150

INTERVIEW WITH HAL KIRSHBAUM

Date of Interview: March 18, 1999

Tape 1, Side A	169
Tape 1, Side B	181
Autobiographical Essay	187

INTERVIEW WITH MICHAEL PACHOVAS

Interview 1: July 7, 1998

Tape 1, Side A	196
Tape 1, Side B	208
Tape 2, Side A	221
Tape 2, Side B not recorded	

Interview 2: August 5, 1998

Tape 3, Side A	232
Tape 3, Side B	252
Tape 4, Side A	272
Tape 4, Side B not recorded	

Interview 3: September 1, 1998

Tape 5, Side A	279
Tape 5, Side B	291
Tape 6, Side A	304
Tape 6, Side B	316

INTERVIEW WITH RAYMOND UZETA

Date of Interview: October 11, 1998

Tape 1, Side A	328
Tape 1, Side B	340
Tape 2, Side A	352
Tape 2, Side B not recorded	

INDEX--Builders and Sustainers of the Independent Living Movement in Berkeley, Volume IV

- Abt Associates, 73-75, 77, 120-122
- Abt, Clark, 73, 121
- ACCD. See American Coalition of Citizens with Disability
- accessibility, 66-67, 175, 259-260, 308, 311, 313; buildings, 243, 331-332, 351-352; historic preservation and, 311-312; transportation, 48, 117-118, 154-155, 233, 333-334; urban planning studies and, 82. See also assistive devices; Coordinating Committee for the Removal of Architectural Barriers; vans, wheelchair accessible.
- ADA. See Americans With Disabilities Act.
- ADAPT. See American Disabled for Attendant Programs Today.
- alcohol use, 45, 199
- American Coalition of Citizens with Disability (ACCD), 337
- American Council of the Blind, 278
- American Disabled for Attendant Programs Today, 56
- Americans With Disabilities Act, 66-67, 124-125, 128, 136, 142-146
- Antioch College, 46, 47-49, 169, 178-179, 190
- architectural barriers. See accessibility, buildings; Coordinating Committee for the Removal of Architectural Barriers.
- assistive devices and technology, 48
- athletics and disability, 264, 317, 330-331. See also Berkeley Outreach Recreational Program (BORP); Indoor Sports Club; Recreation Center for the Handicapped.
- athletics, 203-204
- attendant caregivers, 37-39, 46, 48, 51-52, 53, 233, 239, 241, 244, 318-319, 321; conscientious objectors program, 38. See also Disabled Emergency Services Program.
- Bacon, Betty, 250
- Baker, John, 27-28
- Barker, Linda Toms, 133, 136, 260
- Bay Area Rapid Transit (BART), 48
- Beckwith, Mark, 282, 283
- Berkeley Outreach Recreation Program (BORP), 255, 263, 264
- Berkeley Planning Associates, 120-129, 131-146
- Berkeley, California, 36-37, 44-45, 55-56, 66-67, 86, 119, 184, 238-240, 277, 313. See also disability rights movement, Berkeley, importance of; independent living movement, Berkeley, importance of; Measure E; Braille program school mainstreaming.
- Berrol, Sheldon, 49
- Berry, Don, 10, 332, 333, 344
- Biscamp, Larry, 10, 11, 39, 50, 51, 78-79, 84-85, 245, 246, 260
- Black Panthers, 338
- blindness. See American Council of the Blind; National Federation of the Blind; visual impairment; visually impaired movement.

- BORP. See Berkeley Outreach Recreation Program.
- Boston, disability rights movement in, 295
- Braille program school mainstreaming, 1-2
- Brean, Edna, 41-41, 241
- Breslin, Mary Lou, 314
- Brickman, Gary, 297, 304, 305
- Brown, Janet McEwen, *Int.* 1-26, 245
- Brown, Jerry, 246, 255, 286
- Burton, Congressman John, 338, 339, 340, 341
- Califano, Joseph, 58, 337
- California Association of the Physically Handicapped (CAPH), 331, 332, 343, 346, 349
- California Coalition of Disabled Students (CCDS), 250
- California School of Professional Psychology (Berkeley), 265-266
- California State Department of Rehabilitation, 13, 39, 92-95, 130-131, 241, 330. See also Innovation and Expansion Grants; Roberts, Edward.
- California State Governor's Committee on Employment of the Handicapped, 93-95
- California State Proposition 13 (1978), 265
- California State Propositions 209 and 227, 354
- Californian State Prison (Vacaville), 260
- CalTrans, 333
- Cameron School for the Orthopedically Handicapped (El Cerrito), 264
- Camp Winnarainbow, 303
- Campbell, Jim, 170
- CAPH. See California Association of the Physically Handicapped.
- Carter, President Jimmy, administration of, 282, 285, 294, 300, 337
- Castro, Irma, 353
- Cathcart, Carolyn, 7-8
- CCDS. See California Coalition of Disabled Students
- CCRAB. See Coordinating Committee for the Removal of Architectural Barriers
- Center for Independent Living, Inc. (CIL), 6-17, 19-21, 26-28, 45, 47-59, 87, 89-90, 93, 97, 110, 118-119, 175-176, 178, 185-186, 242, 245, 247, 252-253, 255, 313, 330, 332-336; dissatisfaction with/criticisms of, 256-257, 274-275; establishment 81-92, 108; leadership, 83-84, 88, 116; peer counseling services, 37, 170-177, 179-182, 189-190. See also *Independent, The*.
- Chavez, Phil, *Int.* 33-67, 242
- Chicago, Illinois, 296
- Chicano Federation (San Diego), 351-354
- Chicano/La Raza movement, 354
- CIL. See Center for Independent Living, Inc.
- Circle K Club, 207
- City College of San Francisco, 329, 333, 349-351
- civil rights movement, 188. See also Chicano/La Raza movement.
- Coe College, Iowa, 189
- Coelho, Tony, 281-282, 285-286
- Cohen, Ann, 122
- Cole, Charles (Chuck), 11, 79, 93-94, 106-111
- Collignon, Frederick, *Int.* 72-158
- Community Resources for Independence (Santa Rosa), 21, 23-24
- Community Service Center for the Disabled (San Diego), 336, 351-354
- Computer Training Project, 174
- Cone, Kitty, 335, 336, 339
- conscientious objectors. See attendant caregivers, conscientious objectors program.

- Coordinating Committee for the Removal of Architectural Barriers (CCRAB), 259-260
- Council of State Administrators of Vocational Rehabilitation (CSVAR), 75, 76, 126, 132, 133
- counterculture, attitudes toward, 204
- Cowell Hospital residence program, 40-43, 241, 242, 250, 248-252, 332; transition to dorm and community-living program, 246, 251, 280. See also Physically Disabled Students' Program; Disabled Students Residence Program, UC Berkeley.
- Cowell Hospital, UC Berkeley, 40
- Crystal Springs Rehabilitation Center (San Mateo), 265
- CSCD. See Community Service Center for the Disabled (San Diego).
- Cuba, travel to, 188
- curb-cuts/curb ramps, 16, 41, 66, 82, 86, 331
- D'Angelo, Nancy, 52
- D'Lil, Hollynn. See Fuller, Hollynn.
- DAFR. See Disabled American Freedom Rally.
- Dahl, Dale, 260
- DAV. See Disabled American Veterans.
- Davis, Bob, 45
- Davis, California, 240
- DCHC. See Disabled Community Health Clinic.
- Delancy Street Foundation, 263
- Dellums, Congressman Ronald, 304, 305
- Democratic Party, 282. See also National Democratic Convention of 1968 (Chicago).
- Denver, Colorado, 296
- Department of Labor. See United States Department of Labor.
- Department of Vocational Rehabilitation. See California State Department of Rehabilitation.
- Diablo Canyon Nuclear Power Plant, 308
- Dibner, Eric, 28, 336
- disability:
- attitudes toward, 7, 157, 237, 299, 331, 343, 347-349; culture and community, 60, 64, 186, 234, 252, 330; depression and, 56; developmental, 146, 157; discrimination toward, 23, 127-128, 142, 157, 185, 348; diversity and, 14, 50, 177; educational access and opportunity, 238, 261, 266, 350; employment and, 13, 124-125, 128, 133-136, 154, 315 (see also supported employment; Disabled Students' Career Planning and Placement Program, UC Berkeley); family response, 1, 2, 139-140, 232, 235, 348-349; identities, 111-112, 155, 182; institutionalization and de-institutionalization, 56, 229; media (see *Independent, The*; *Disability Rag, The*); onset and adjustment to, 34, 36, 56, 217-231, 232-233, 237-238, 329, 349, 351; public policy research on, 122-129 (see also Abt Associates; Berkeley Planning Associates); race discrimination and, 105-106, 124, 154, 276; racial and ethnic minorities and, 347-349; self-esteem and, 262, 311, 317; sexuality and, 36, 43, 265
- Disability Center, UC Berkeley, 107
- Disability Rag, The*, 90, 95, 96
- Disability Rights Education and Defense Fund, 255

- disability rights movement, 15-16, 25-26, 56-58, 61-64, 93-94, 106, 234, 244, 247-248, 252, 263, 267-278, 291-292, 294-296, 309-312, 317, 338, 340; Berkeley, importance of, 310-315, 332, 343-344; coalition building in, 14-15, 90, 291, 294, 296-298, 307-312; comparison with/ relationship to other movements, 25, 155, 261, 269, 281, 289-290, 308, 343; history of, 108; leadership training and development, 97-98, 116-117, 313-318; leadership of, 255, 269, 343-345; lobbying and lobbyists, 61-64, 75, 88, 96, 114-115, 294, 338, 340; reflections on, 65-67, 153-158; sectarianism in, 89, 245, 246, 267-268, 291, 295, 352. See also Disabled American Freedom Rally (DAFR); Rehabilitation Act of 1973, San Francisco sit-ins; visually impaired movement.
- disability rights, as a civil rights issue, 24-25, 102-103, 234-235, 261, 311, 316, 343-345
- disability rights, legislative action/process, 96, 98-103, 136, 332. See also Rehabilitation Act of 1973, Americans With Disabilities Act.
- Disability Studies Program, UC Berkeley, 148-151
- disability studies, 79, 151-152, 316. See also disability, public policy research; National Institute on Disability and Rehabilitation Research; Wright Institute; Antioch College West.
- Disabled American Freedom Rally (DAFR), 268, 290-310
- Disabled American Veterans (DAV), 234
- Disabled Community Health Clinic, 46, 52
- Disabled Emergency Services Program, 318-323
- Disabled Prisoners' Program (DPP), 255, 260-264
- Disabled Students' Program. See Physically Disabled Students' Program; Cowell Hospital residence program.
- Disabled Students' Union, 46, 52, 64-65, 243-244, 246, 260, 263, 271-272, 280
- Disabled Women's Coalition, 267
- DPP. See Disabled Prisoners' Program.
- DR. See California State Department of Rehabilitation.
- Draper, Phil, 10, 11, 12, 27, 51, 84, 91, 332, 333
- DREDF. See Disability Rights Education and Defense Fund.
- drugs, recreational use and abuse of, 41-43, 45, 298, 304-306; therapeutic/medicinal use and abuse of, 231, 236. See also alcohol, use of.
- DSP. See Physically Disabled Students' Residence Program.
- DSU. See Disabled Students' Union.
- Duggan, Catherine, 20-21
- Duhl, Len, 148
- education, importance of, 124, 154
- Edwards, Harry, 258
- Ellsberg, Dan, 287
- environmental movement, 279-290, 294
- Erickson, Milton H., 191
- Ethiopia, 204, 205-219
- ethnicity, American experiences of, 198-201
- Fair Employment Practices Commission (FEPC), 17-18

Fantin, Dennis, 242, 250, 280, 281, 284
 FBI. See Federal Bureau of Investigation.
 Federal Bureau of Investigation (FBI), 297-302
 FEPC. See Fair Employment Practices Commission.
 Finnegan, Patty. See Wright, Patty.
 First Congregational Church, Berkeley, 48
 504 Regulations compliance units, 351-352. See also Rehabilitation Act of 1973, 504 Regulations.
 Friends of the River, 279, 285
 Froebel High School, Gary, Indiana, 198, 200
 Fry, Sid, 260
 Fuller, Hollynn, 251
 Fuss, Michael, 242

Galloway, Don, 15, 174, 182, 260
 Gary, Indiana, 197-198, 200-201
 gays and lesbians, 341
 gender relations and disability, 248
 George, Michael, 233
 Gill, Gary, 27-28
 Gonsalves, Manuel, 352
 "Good Morning America," 284-285
 Goodwyn, Karen Topp. See Topp, Karen.
 Gordon, Marty, 75
 Gore, Albert, 122
 Gorman, Walter, 241, 252
 Governor's Committee on Employment of the Handicapped. See California State Governor's Committee on Employment of the Handicapped.
 Graham Lata amendment, 268, 292, 303-304, 307
 Grimes, Charles (Chuck), 242
 Grimes, Ruth, 82
 Gutierrez, Felix, 348

Hahn, Harlan, 149
 Harveston, Dominic, 173
 Health Education and Welfare, U.S. Department of, 136. See also Rehabilitation Act of 1973, San Francisco Sit-in.
 Hell's Angels, 63
 Hessler, John, 90, 95-97, 242-243, 245-246, 250, 313, 332, 333, 343, 344
 Heumann, Judith E., 52, 79, 116-120, 313, 337-339; leadership at Center for Independent Living, 9-10, 27, 182, 253-254
 Highland Hospital (Oakland), 350
 Hiserman, Mary Ann, 51, 248
 Hispanics, disability and, 347-348
 Holy Names College (Oakland), 4, 23
 Howson, George, 9

IHSS. See In-Home Support Services.
 independent living, 26, 46, 54-56, 87, 99, 109, 125-126, 229, 234; move from Cowell Hospital to community apartments, 81-82, 251; policy studies on, 92, 123-129, 131-133. See also Center for Independent Living; independent living movement; independent living centers.
 independent living centers, 21, 131-132, 306, 345-347
 independent living movement, 24, 51, 91, 115, 184-187, 344, 354; Berkeley, importance of, 38, 86, 91, 252. See also Center for Independent Living; disability rights movement.
 Independent, The, 8-9, 26
 Indiana University, Gary, 205
 Indoor Sports Club, 331, 332, 349
 In-Home Support Services, 61-64, 332
 Innovation and Expansion Grants, 345-346

Institute of Urban and Regional
Development, UC Berkeley, 79
interstate truckers, 297-299

Jackson, Jane, 301-302
Jay, Cathy, 242
Jones, Lennis, 51

Kaiser Hospital Rehabilitation
Center, Vallejo, 35
Kaiser Permanente Health Care,
140-141
Keller, Russ, 203-204
Kennedy, Congressman Ted, 304,
305
KGO-TV (San Francisco), 338
King, John, 345, 346
Kirshbaum, Anya, 189
Kirshbaum, Hal, *Int.* 169-187;
biographical essay, 187-191
Kirshbaum, Megan Light, 172, 179,
180, 183, 186, 189, 191
Kirshbaum, Noah, 191
Knight, Susan, 342, 346
Konkel, David, 5, 79, 88-89, 114-
115
Kowalsky, Sharon, 307
Krieger, Martin, 121
Kurtz, Leeann, 263

Langdon, Lawrence (Larry), 51,
245, 246
LaPlant, Mitchell (Mitch), 144
Leach, Skii, 349-350
Leech, Peter, 52
Lennox, Andrew, 242
Leon, Joan, 26-27
Leroy, Lauren, 140
lesbian community, 27, 341
Liebowitz, Herb, 93
Livermore Action Committee, 308
Lorence, Donald, 40, 51, 242, 313
LSD. See drugs, recreational use
of.
Luebking, Scott, 46
Lyndstrom, Tom, 45

Maher, John, 263
mainstreaming, educational, 1-2
Making a Blind Man, 111-112
Maldonado, Joseph, 337, 341
marijuana. See drugs,
recreational use of
Marin County, California, 105,
127-128
Marks, Senator Milton, 342
Martin, Douglas, 352
Martin, Michelle, 298
McBride, Paul, 251
McCarthy, Leo, 338, 341
McElmore, Steve, 258
McEwen Brown, Janet. See Brown,
Janet McEwen
Measure E, 320-322
medical experimentation and
disability, 261
medical profession, disabled
attitude toward, 228, 332
mental health care, rehabilitation
services and, 140
mentally ill, discrimination
toward, 127-128, 157
Metts, Bob, 79, 93-94, 97, 280,
281, 284
Michael Reese Hospital, Chicago,
228
Miller, Congressman George, 338,
339
Montgomery, Roger, 258
Morton, Jean, 150
Moscone, George, 338, 341
Moyer, Jeff, 28, 182, 351
Mullin, Jim, 149
multiple sclerosis (MS), 170,
188-189
Murphy, Congressman Austin, 303
myasthenia gravis, 330, 349

Nadell, David, 241, 251,
National Democratic Convention of
1968 (Chicago), 201, 207
National Federation of the Blind
(NFB), 1, 5-7, 278
National Institute of Mental
Health, 265

- National Institute on Disability and Rehabilitation Research, 149
- National Paraplegic Foundation (NPF), 234, 277
- National Wild and Scenic Rivers Act, 286, 288
- Neighborhood Services Program, 73
- Newman, Ed, 74-77, 80, 86-88, 96-101, 103, 114, 121
- Newsome, Karen. See Topp, Karen.
- NFB. See National Federation of the Blind.
- NIDRR. See National Institute on Disability and Rehabilitation Research.
- Nixon, Richard M., presidency of, 77, 98-100
- Noble, Jack, 95
- NPF. See National Paraplegic Foundation.
- O'Hara, Susan, 64
- O'Grady, Mary Ellen, 260
- Okuno, Ken, 9
- osteo imperfecta, 349
- Owen, Mary Jane, 295, 300, 301
- Pachovas family, 196-200, 232, 233, 240; (father), 198, 224, 233, 235, 236; (mother), 198-199, 223, 224, 225, 226, 233, 235-236
- Pachovas, Michael, 45, 46, 51, 61, 335; *Int.* 196-323
- Padilla, Genaro, 149
- Paralyzed Veterans of America, 234
- parenting and disability, 186, 191. See also Through the Looking Glass.
- Parker, Karen. See Topp, Karen.
- PDSP. See Physically Disabled Students' Program.
- Peace Corps, 204, 205-219, 227, 235
- Pechen, Jim, 338
- pediatric care and disability, 139-140
- peer counseling, 24, 36-37, 54-56, 87, 330-331. See also Center for Independent Living, peer counseling services.
- peripheral neuropathy, 329-330
- personal politics and disability, 228, 234, 235, 244
- physical education, 204
- Physically Disabled Students' Program, 4, 6, 39-41, 45, 52, 64, 85-86, 176, 241-248, 252, 263, 313, 332, 344. See also Cowell Hospital residence program; Rolling Quads.
- Pittsburgh, Pennsylvania, 296
- Platt, Tony, 258
- power wheelchairs, 38, 40-41, 236, 242-243
- Pransky, George, 12
- President's Committee on Employment of the Handicapped (now called President's Committee on Employment of People With Disabilities), 295, 300
- prisoners' rights movement. See Disabled Prisoners' Program; California State Prison, Vacaville.
- quadriplegics, unique medical vulnerabilities of, 230, 276
- rational planning models, 258-259
- Reagan, Ronald, 93-95; gubernatorial administration, 293; presidential administration of, 282, 290, 292, 293-294, 297, 300-301, 302.
- Recreation Center for the Handicapped (San Francisco), 330, 349

- Rehabilitation Act of 1973, 73, 79, 88, 96-103, 123, 136-137; 504 regulations, 16-17, 337; San Francisco sit-in, 58-61, 183, 336-343; Title VII, 131-138; Washington D.C. demonstrations, 100-101
- Rehabilitation Institute of Chicago, 228-229, 232
- Rehabilitation Services
Administration, 74-77, 78, 123, 133; "Berkeley independent living model," 87, 96; "Texas care facility model," 87
- rehabilitation services, 21-22, 99-100, 105-106, 109, 117-119, 123-124, 137-138, 140-142. See also California State Department of Rehabilitation; Kaiser Vallejo Rehabilitation Center; Rehabilitation Institute of Chicago; Rehabilitation Services Administration; Stanford Hospital.
- rehabilitation, definitions of, 146-148
- rehabilitation, personal experiences with, 36, 227-231. See also Kaiser Vallejo Rehabilitation Center, Stanford Hospital; Rehabilitation Institute of Chicago.
- religious faith, 216-218
- residence program. See Cowell Hospital residence program; Physically Disabled Students' Program, UC Berkeley.
- Reynolds, Esther, 260
- Richardson, Elliot, 98
- Richey, Hanoi, 51
- Richmond, California, 34
- river rafting and disability, 279-280, 288-289
- Riverside Church, New York, 302
- Roberts, Edward V., 27, 41, 50, 63, 82-83, 84, 242, 245, 252, 253-257, 267, 311, 313, 332, 333, 343-345;
- Roberts, Edward V. (cont'd)
Center for Independent Living director, 9-12, 19-21, 170, 171, 247, 335; Department of Rehabilitation director, 64, 129-131, 246, 249, 255, 266, 332, 346
- Roberts, Zona, 242, 313
- Rolling Quads, 45
- Romney, Hugh. See Wavy Gravy.
- Rowan, John (Jack), 332
- RSA. See Rehabilitation Services Administration.
- Rutledge, John, 251-252, 252
- Safeway, Inc., 338
- Salt Lake City (Utah), 296
- Sanders, Greg, 37, 39, 51
- Santos, Dick, 5, 7-8, 245
- Save the Rivers, 283, 285, 287-288
- Schon, Donald, 112-113
- School for the Deaf and Blind, Berkeley, 2, 89
- Scott, Donald, 111-112
- senior citizens, transportation for, 334
- Seva Foundation, 303
- Sierra Club, 282, 285, 290
- Small Business Administration, 145
- Social Policy Studio, UC Berkeley, 77-84
- Soucy, Connie, 337, 338, 340
- Sparks, Bob, 297-299, 307
- Sparks, Shitara, 298
- Spiegler, John, 230, 231, 232
- Spitler, Rick, 282
- SSI. See Supplemental Security Income.
- St. Charles School (San Francisco), 26
- Stanislaus River, damming of, 288
- Stanislaus Wilderness Action Committee, 279, 281, 300
- Stein, Ken, 9, 49, 336
- Stoddard, Sue, 111, 133
- Students for a Democratic Society (SDS), 207

- Supplemental Security Income, 65, 262, 332
- supported employment/sheltered workshops, 13, 143-145, 155-156
- Sutton, Mark, 279-280
- Synanon, 263-264
- Sygall, Susan, 263
- Tainter, Bill, 330, 347, 351, 352, 353
- Taylor, Judy, 40, 51, 79, 97, 104, 241-242
- ten Broek, Jacobus, 1-2, 108
- Thayler, Sandra, 52
- Thompson, Barbara, 88, 108
- Through the Looking Glass, 173, 179, 181, 184
- Tietz, Michael, 121
- Topp, Karen, 249-251, 260
- traumatic spinal cord injury, 40, 56, 173, 215-227, 229-230, 234, 266, 276
- Trier, Peter, 253
- Turem, Jerry, 95
- Turkey, 221-222
- Tussman Program, UC Berkeley, 3-4
- UCPA. See United Cerebral Palsy Association.
- Union Graduate School, 179, 189, 190
- United Cerebral Palsy Association (UCPA), 345, 346
- United Nations Year of the Disabled Person, 290-291, 292
- United States Air Force medical center, Andrews Air Force Base, 227-228
- United States Army, 219-222; Weisbaden Army Hospital, Germany, 224-227
- United States Army Corps of Engineers, 279, 281, 289
- United States Congress, 303. See also Graham Lata amendment.
- United States Department of Labor, 133-134, 142, 238, 249, 266
- United States Office of Civil Rights, 16-17
- University of California, Berkeley, 3-5, 41, 77-84, 116, 250, 311, 313, 329, 333; access and mobility at, 40-41, 43, 243, 246, 259-260; decision to attend, 238-239; Disability Studies Program, 148-151; diversity issues, 103-105; institutional response to disability, 41, 95; radical education at, 257-259. See also Cowell Hospital; Disabled Students' Residence Program; Physically Disabled Students' Program, UC Berkeley.
- University of California, San Francisco Medical Center, 265
- University of San Francisco Rehabilitation Administration program, 79-81, 107-108, 329, 351
- University Without Walls (state employees higher education program), 190
- Uzeta family, 328
- Uzeta, Ray, *Int.* 328-355
- vans, wheelchair accessible, 93, 117, 249, 266
- Velton, John, 251
- Vietnam veterans. See United States Army, Weisbaden Army Hospital; United States Air Force medical center, Andrews Air Force Base.
- Vietnam War, draft, 202-205; medical treatment, 224, 227; opposition to, 38, 207-208, 252
- Vincel, Mary, 136
- visual impairment, 5, 111, 113. See also *Making a Blind Man*; McEwen, Janet.
- visually impaired movement, 6, 89, 114-115, 277-278

- Vocation and Rehabilitation Act,
review of, 76
- Vocational Rehabilitation of the
Severely Disabled in a
University Setting. See
Rehabilitation Research
Reports.*
- vocational rehabilitation
programs, federal funding of,
292-293, 303-304
- Vocational Rehabilitation,
Department of. See California
State Department of
Rehabilitation.
- voucher system, rehabilitation
services and, 117-119, 137-
138; schools and, 118-119
- Washington, D.C., 187-188
- Wavy Gravy [Hugh Romney], 303,
304, 308
- Weeks, Cece, 46, 51, 248
- Weicker, Congressman Lowell, 303,
305
- Welfare Reform Movement, impact on
disabled, 317
- West, Bronson, 251, 307
- Westside Center for Independent
Living (Los Angeles), 352
- wheelchairs, 236, 284. See also
power wheelchairs
- Whitman, E. B., 76
- WID. See World Institute on
Disability.
- Wildavsky, Aaron, 88-89
- wilderness access, disability and,
290
- Wilkinson, Judy, 5
- Willsmore, Herbert (Herb), 51,
79, 85, 97, 241-242
- Wilson, Governor Pete, 353
- Winter, Michael, 53
- women's issues, 104
- workers' compensation,
rehabilitation services and,
137, 141-142
- World Institute on Disability,
27, 148-149
- Wright Institute, Berkeley, 177-
178
- Wright, Patty, 8
- Yelin, Edward (Ed), 144
- Zanella, Raymond, 250, 347, 351
- Zukas, Hale, 17, 335, 336

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Disability Rights and Independent Living

Movement Oral History Series

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